SAR Brenda

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1. Introduction

1.1 Brenda was aged 75 years when she died on 03/02/21 in hospital, after several weeks of accelerating deterioration at home. From Christmas Eve 2020, Brenda withdrew from essential activities of daily living. The first signs of this were neglect of the home environment with rotting food and milk and a build-up of unwashed dishes. By 14/1/21, the visiting community nurses were concerned about poor food, and possibly poor fluid, intake. Conditions were exacerbated by the results of unmanaged incontinence of faeces, visible about the home and on clothes, on the bed and on Brenda.

1.2 Brenda lived alone, did not go out, and wanted to avoid Covid 19 exposure. Brenda was estranged from her son, for reasons that were not explored at the time. In the past he had arranged food deliveries for her but there was otherwise not a known history of family involvement with Brenda. On 2/2/21 when Brenda was extremely ill and being taken to hospital, her son could not be notified since there was no current telephone number on record.

2. SAFEGUARDING ADULT REVIEWS

2.1 Section 44 of the Care Act 2014 places a statutory requirement on the Swindon Safeguarding Partnership to commission and learn from SARs (Safeguarding Adult Reviews) in specific circumstances, as laid out below, and confers on the Board 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

'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) the adult had died, and the SAB knows or suspects that the death resulted from abuse or neglect…, or

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.

2.2 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).

2.3. The purpose and underpinning principles of this SAR are set out in the Swindon Safeguarding Adults Policy and Procedure.

2.4 All SSP 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").

2.5 This case was referred to the Practice Review Sub-group of the SSP on 04/02/2021 and considered for a Safeguarding Adult Review at the meeting on 30/04/2021.

2.6 The Practice Review Sub-group considered this case as meeting the criteria for a SAR, and the SSP Executive ratified this 12/05/2021

2.7 The Safeguarding Adults Review was led by Patrick Hopkinson who is an Independent Consultant in Adult Safeguarding and who had no previous involvement with this case and no connection to the Swindon Safeguarding Adults Board, or its partner agencies.

2.8 Brenda's son was contacted and invited to take part in the review.

3. BRIEF SUMMARY OF CHRONOLOGY AND CONCERNS

3.1 Brenda had numerous physical health conditions and awaited investigation for heart failure due to, worsening oedema, breathlessness and poor renal function due to chronic kidney disease. The outpatient record also listed ischaemic heart disease, Sjogren's syndrome (symptoms of tiredness, with dry eyes and mouth); iron deficiency anaemia and musculo-skeletal pain. Brenda had past hyperuricemia (high levels of uric acid; a frequent precursor of gout).

3.2 Brenda appears to have been socially isolated and was only able to access the ground floor of her home. Being alone at Christmas may have worsened what Brenda called her “low mood”. She was on medication for depression but had stopped taking it for an unknown length of time. There were no other interventions to support Brenda’s mental health. There is no biographical information available.

3.3 Concerns about Brenda’s reduced ability to look after her home were first noted by a community nurse on Christmas Eve 2020. It was not unusual for Brenda to have items out on the floor, but on this occasion the attending clinicians felt that there was a risk of significant harm. Food had been left rotting and there were unwashed dishes in the kitchen. Brenda could not answer questions about her food intake. Signs of unmanaged incontinence meant that there were faeces on surfaces, Brenda’s skin, her bedding and clothes.

3.4 As Brenda’s condition worsened, community nurses offered to bring in support. Brenda consistently told the nurses that the situation was caused by her “low mood”, which she would come out of as she had before without help.

3.5 Brenda continued to refuse any outside involvement throughout this period including contact with her son, only seeing the weekly community nurses who on occasions involved practitioners from the GP surgery.

3.6 On 14/01/21 two practitioners from the Community Nursing Team visited Brenda. Both shared their concerns with Brenda and on multiple occasions offered to help or to seek help for her. Brenda was adamant that she did not want any help or anyone to know of their findings in her home. The practitioners believed that Brenda had the mental capacity to make the decision to decline help, although a mental capacity assessment was not completed at this stage. When asked, Brenda did not give consent for a safeguarding referral to be made.

3.7 Following discussion with their line manager, on 14/01/21 nurses raised a safeguarding concern with adult social services without Brenda’s consent due to their concerns about her safety. They advised the safeguarding team that they believed that Brenda was self-neglecting. The concern was received, and the safeguarding team contacted Brenda by telephone who said she would accept support. The safeguarding team referred Brenda to the Initial Contact Team (ICT), which offered to assess Brenda by telephone, since visits were only made when there were very high risks which could not be managed in other ways.

3.8 On 15/01/21, the safeguarding team left a message for the nurse who had raised the concern to telephone them back. On 18/01/21, the adult social services safeguarding team

concluded that the s42(1) criteria for a statutory safeguarding enquiry had not been met and noted that the ICT had been asked to visit Brenda as soon as possible.

3.9 On 21/01/21 Brenda assured the visiting community nurse that she was eating and taking medication, but little housework had been done. Brenda was asked about eating and drinking and said that she had been eating small amounts. Brenda was given a glass of water and two slices of cake which she ate. After initial refusal, Brenda was supported with personal care and the community nurse put on washing for her, which Brenda said she would sort out later when it had finished. Brenda washed faeces from her hands and walked back to the bed. Brenda stated she had taken her medication.

3.10 The community nurse contacted the adult social services safeguarding team and was updated on progress. Following this on 21/01/21, the safeguarding team emailed the ICT stating that Brenda urgently required a package of care. The ICT manager replied that there was currently a two-to-three week turn around and Brenda would be allocated as soon as possible. The ICT emailed the Community Response Hub and on 22/01/21, a case note recorded that Brenda was with the "pre-assessment" team. A non-recorded decision was made for the ICT to investigate further but there was no outcome until 2/02/21. Brenda's case then became stalled in the Adult Social Care system.

3.11 On 21/01/21, nurses contacted the GP surgery with concerns about Brenda's mental health, self-neglect, home environment and that she was not eating or drinking. On 25/01/21, a GP telephoned Brenda but received no answer. No further telephone calls were made by the GP.

3.12 At the next visit on 28/1/21, the community nurse described the insanitary condition of Brenda's home as being at a crisis point. Brenda had increasingly taken to her bed, looked undernourished from not eating, was drinking little, and was unable to manage her continence needs. She was running out of clothes and bedding. Food from before Christmas and unwashed dishes were rotting in the kitchen. Brenda continued to decline outside involvement including family contact.

3.13 Following contact with the GP surgery that same day, an ambulance was called but did not take Brenda to hospital as she refused to go. There was no assessment of Brenda's mental capacity to refuse conveyance to hospital or admission. The ambulance service reported the self-neglect concerns to adult social care via email and to Brenda's GP.

3.14 The Advanced Clinical Practitioner (ACP) from the GP surgery visited on 29/1/21, since Brenda was still considered to be at risk. Although Brenda sounded well on the telephone, she was covered in blankets and her dressing gown was stuck to her skin with faeces. Brenda was now not walking to the kitchen. After some encouragement Brenda agreed to contact with adult social care but the local authority call handler explained the waiting list and e-mailed the duty social worker.

3.15 The ACP tried to get support for Brenda and sent a request to Rapid Response that afternoon but this was not logged nor acted on. The ACP also gained an agreement from the out of hours social care emergency duty service (EDS) for a visit the next day (a Saturday). The EDS telephoned Brenda who gave reassurances that she was ok. As a result, the visit did not then take place. No assessment of Brenda's mental capacity was made.

3.16 On 2/2/21 Brenda had been alone for three days when next seen during a joint visit by the ACP, the community nurse and a social worker from the Initial Contact Team. The conclusion was unanimous that Brenda was in an unsafe setting. The social worker assessed Brenda as lacking the mental capacity to make decisions about her safety. Brenda at this stage appeared to be seriously ill: cyanosed, with signs of dehydration and a distended, hard and tender abdomen. Brenda had physical signs of immobility and extensive sores.

3.17 Brenda was taken to hospital but died the next day of multi-organ failure and sepsis, with a finding of cirrhosis of the liver. There was no known history of alcohol misuse. Brenda had never disclosed, and practitioners had not noticed any signs of, previous or current alcohol use.

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 an analysis of research, practice guidance, legislation and policy and procedure will be used to provide an analytical framework within which practice with Brenda can be understood.

4.4 **Self-neglect.**

4.5 Research by Braye, Orr and Preston-Shoot first brought focus to the subject of hoarding and self-neglect in the UK. (Braye et al, 2011). Since then, lessons from the growing research and practice experience have led to the development of principles and guidance for ethical and effective practice. This draws on person-centred and strengths-based work and on the exercise of professional curiosity and the use legal literacy, as there are a range of powers and duties in addition to those within the Care Act 2014 and The Mental Capacity Act 2005 and their Codes of Practice.

4.6 **The national and local picture of SARS and Self Neglect Best practice**

4.7 Preston-Shoot reviewed 195 recent SARs concerning self-neglect. (Self-Neglect and Safeguarding Adult Reviews: Towards a Model of Understanding Facilitators and Barriers to Best Practice M Preston Shoot). There are themes common to Brenda and also to some previous Swindon SARs (for example SARS Alison, Kieran and Terry). Preston-Shoot

organised lessons from SARs into domains including the individual, the team around them and the organisations involved.

4.8 Domain A: The Individual. Effective practice included themes of using approaches that are person centred, showing empathy and developing relationships; emphasising continuity and maintenance of contact rather than case closure; balancing authoritative approaches with gentle persistence; using good questioning and gaining knowledge of personal history and context; involving family and advocates; questioning why a person refuses support and assessment and considering risks, needs and mental capacity including executive capacity; recognising that verbal ability is does not mean that someone is making a capacitous decision; using legal literacy.

4.9 Domain B: The Team around the adult. Effective practice included themes of Not working and silos and using interagency communication and collaboration; using a lead agency/key worker approach, holding multi-agency meetings especially for risk management plans; thorough information sharing; safeguarding is understood and used, including the duty to enquire; evidence of the use of the self-neglect policy and procedures; access to advice on law, mental capacity and mental health and good case recording.

4.10 Domain C: Organisations around the professional team: Themes include commissioning of a range of services for people who self-neglect; managers demonstrating, and recording, case oversight.

4.11 **ADASS Guidance on Self-Neglect Practice**

4.12 The Learning Support Document, Self-Neglect and Hoarding (ADASS East of England Safeguarding Adults Network 2020) draws from the work of Braye, Preston-Shoot and Orr and uses a series of case studies to provide guidance for practitioners.

4.13 Three broad themes emerge:

4.14 **Developing person centred approaches** means building rapport and trust, exploring what lies behind the presentation of self-neglect and respectful challenging to learn more. There are reasons for self-neglect which can include cognitive problems, trauma or loss. Workers need curiosity and persistence to balance patience with taking advantage of opportunities for change. The person who self-neglects and those around them such as their GP and family should be involved. This is fundamentally a strengths-based approach. (Strength Based Approaches for Working with Individuals. L Pattoni-Iriss 2012).

4.15 **Multi-agency work is essential** as no agency has all the answers. Pooling expertise and sharing information and concerns, working through problems as a group is a key component of effective work. A safeguarding multi-agency approach may be appropriate and judgement is needed to decide strategies and to balance the sometimes conflicting priorities of autonomy and protection and when to use person centred or assertive approaches.

4.16 **Strong risk assessments** must be undertaken and recorded, using evidence collected independently of the person who self neglects own reports. Each risk should be identified and their likelihood, significance and impact recorded and the assessment regularly updated. Risk assessments should identify meaningful outcomes and should be reviewed. Events

should not be considered in isolation but patterns and cycles should be identified and interventions escalated as risks increase. Legal powers and duties should be emphasised in assessments.

4.17 The research and practice guidance outlined above will be used to provide an analytical framework for understanding the effectiveness of different agencies interactions with Brenda.

4.18 **The Care Act 2014**

4.19 Section 1 of the Care Act (2014) states that, "The general duty of a local authority, in exercising a function under this Part in the case of an individual, is to promote that individual's well-being". A definition of well-being is provided (see appendix 1) but for the purposes of this review, it is sufficient to note that well-being includes personal dignity (including treatment of the individual with respect); physical and mental health and emotional well-being; and suitability of living accommodation

4.20 Section 9 of the Care Act (2014) states that where is appears to a local authority that an adult may have needs for care and support, the authority must assess (a) whether the adult does have needs for care and support, and (b) if the adult does, what those needs are. This Care Act duty applies regardless of the authority's view of (a) the level of the adult's needs for care and support, or (b) the level of the adult's financial resources. The Care Act also empowers local authorities to meet urgent needs without an assessment (section 19, Care Act 2014).

4.21 Needs are assessed, within set eligibility domains and, if unable able to meet those needs in two or more domains has a substantial impact on wellbeing, the person is entitled to support to meet need. The principle of well-being includes prevention of a situation worsening.

4.22 There is also a principle of representation and advocacy in response to difficulties engaging with services.

4.23 Section 42 Safeguarding of the Care Act 2014 sets out the duty to make enquiries to decide whether action should be taken where a person referred has needs for care and support, is experiencing or at risk of abuse or neglect and as a result is unable to protect themselves from abuse or neglect. Self-neglect is one of ten categories of abuse and neglect included in the Care Act Statutory Guidance.

4.24 The Guidance defines self-neglect as "Where someone demonstrates lack of care for themselves and or their environment and refuses assistance or services. It can be long-standing or recent".

4.25 **The Mental Capacity Act 2004**

4.26 All the contacts with Brenda took place within a policy context that emphasises choice, independence and personal control and which forms part of an overall neo-liberal Government led approach to adult social care and welfare (Ward et al, 2020).

4.27 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 19981, the Care Act 20142, the Mental Capacity Act3 and the Mental Health Act 1983.

4.28 At the intersection of all 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 is question of prioritising freedom of choice or prioritising protection from harm (essentially Articles 8 and 2 of the Human Rights Act 1998). The guidance on working with people who self-neglect helpfully challenges the either/ or nature of this question by asking practitioners to consider:

4.29 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 are worth anything different.
c) 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.

4.30 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.

4.31 The Mental Capacity Act 2004 (MCA) offers protection for citizens against arbitrary decisions made on their behalf, providing a methodology for determining capacity after all efforts have been made to assist in decision making and for making ethical Best Interests decisions when required. To have capacity to make a decision, the person must be able to understand, retain, use and weigh up relevant information and communicate their decision. Incapacity decisions must link to "A disturbance in the functioning of a person's mind or brain".

4.32 An unwise decision does not mean that a person lacks the mental capacity to make that decision but a series of similar decisions with harmful consequences may require taking a long view, considering mental capacity as a "video" rather than as a "snap shot". A person may lack the executive capacity to follow through on what they decide, or may not be fully understanding or really weighing up relevant information in the decision itself. People can seem to be making choices that are very harmful including self-neglect, but serious neglect is not a lifestyle choice (Safeguarding Vulnerable Dependent Drinkers England and Wales Mike Ward and Professor Michael Preston-Shoot December 2020).

4.33 **Decisional and Executive Capacity**

4.34 The extent to which a person who self neglects can put whatever decisions they make into effect should also be considered. In Brenda's case there were concerns about her ability to self-care and to accept support. 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.

4.35 There is also growing evidence of the impact of long-term trauma, alcohol and substance use and mental health problems on cognitive ability and especially on executive brain function (which includes working memory, mental flexibility, and self-control and regulation) which in turn impacts on mental capacity. Of relevance is that, compared with control groups, people with impaired executive brain function:

- 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.

4.36 As a result, people with impaired executive brain function 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.

4.37 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 Brenda's mental capacity were made. Brenda was treated for depression and at post-mortem was found to have cirrhosis of the liver, the most frequent causes of which are hepatitis or alcohol consumption.

4.38 **Professional Curiosity**

4.39 Professional curiosity is a term applied to the key interpersonal skills and behaviours found absent in numerous SARs relating to self-neglect. It is "the capacity and communication skill to explore and understand what is happening…enquiring deeper and using proactive questioning and challenge understanding one's own responsibility and…when to act". (Professional Curiosity Guidance Norfolk Safeguarding Adults Board April 2020).

4.40 Curiosity is the professional practice of critical reflection, "a process which helps you gain insight into your professional practise by thinking analytically about any element of it. The insights developed, and lessons learned, can be applied to maintain good practice." (HCPC website). It involves noticing and questioning including self-questioning. Reflection and curiosity help eliminate bias including confirmation bias (The Ten Pitfalls and How to Avoid Them. K Broadhurst et al NSPCC 2010).

4.41 The Norfolk Safeguarding Adults Board developed guidance and identified barriers to work with self-neglect that may be overcome through professional curiosity:

- Risks seen discretely rather than as part of an interconnected pattern.
- Normalisation: Staff exposed to extreme presentations may unwittingly get used to and minimise the dangers.

- Confirmation bias: quickly coming to conclusions and not then discounting contradictory evidence.
- Dealing with uncertainty: there is always conflicting or incomplete information in complex cases. Being open minded and self-aware, good communication and information gathering and triangulation of evidence is advised. Practitioners should observe as well as listen.

5. THEMATIC ANALYSIS

5.1 Brenda's Mental and physical health

5.2 Brenda had previous episodes of depression with periods of feeling low which had affected her functioning at home, but these had not been to the extent recognised in January 2021. Brenda's only mental health treatment was the anti-depressant Fluoxetine, which she had stopped taking. Brenda had not been seen by the GP for a year and it does not appear that any reviews had been requested. On 7/01/21 community nurses offered to contact Brenda's GP on her behalf but Brenda refused this. On 14/1/21, a community nurse contacted Brenda's GP to make them aware that Brenda was not taking the prescribed Fluoxetine, although Brenda was unhappy about them doing this.

5.3 Brenda lived alone and had no known visitors, except weekly community nurses to give her an Eprex injection (for haemoglobin). She had also recently become estranged from her son. The impact of loneliness on older people's health is well known, although it is a difficult status to admit to. The World Health Organisation has stated "Social isolation and loneliness are harmful. They shorten older people's lives and damage their mental and physical health and quality of life." (Advocacy Brief Social Isolation and loneliness among older people WHO 29/7/2021; accessed on line 1/3/22).

5.4 Age UK found a correlation between loneliness and depression in older people, seeking ways to alleviate the problem. (Age UK, 2016. Testing Promising Approaches to Reducing Loneliness cited on Age UK website). One key message is listening and exploring what is happening for the individual.

5.5 Brenda had no psycho-social interventions for depression or isolation during the period covered by this review. A community nurse offered to contact Brenda's GP about her low mood, but Brenda refused this. The community nurses appeared to have a specifically medical role and, whilst the rift between Brenda and her son may have affected Brenda, especially at Christmas, its affect and impact on Brenda does not appear to have been explored.

5.5.1 Brenda also lived with significant physical health needs: heart disease, iron deficiency anaemia, Sjogren's syndrome, Musculo-skeletal pain and chronic kidney failure. Post-mortem, Brenda was found to have cirrhosis of the liver. Such a combination could have had an impact on Brenda's energy levels and motivation with likely fatigue and possibly cognitive effects. There was, however, no evidence that Brenda was drinking alcohol.

5.5.2 Mental and physical health difficulties frequently co-exist. Brenda was not recognised as having a complex clinical presentation although she had several long-term conditions but no coordinated approach, in line with the Nice Guidelines (Older People Social Care Needs and

Multiple Long Term Conditions, NICE 2015), appears to have been used. The extent of Brenda's illnesses do not appear to have been recognised until her death.

5.6 Recognition that Brenda was self-neglecting:

5.7 Brenda demonstrated some of the factors of self-neglect outlined in the ADASS Practice Guide. She had a lack of self-care to an extent that it threatened her personal health and safety; she was neglecting to care for her personal hygiene, health and surroundings (and this became apparent by 14/1/21) and was unable to avoid harm as a result of self-neglect. Brenda' also did not, "…seek help or access services to meet health and social care needs".

5.8 Brenda was identified as self-neglecting by the community nurses, because of her refusal to accept outside support when not managing her home or her self-care. By 14/1/21 this had reached what a community nurse described as, "a level of risk". This was accepted by the safeguarding team and was the key issue recorded by the ambulance crew which attended on 28/1/21 when a "crisis point" was flagged by the community nurse.

5.9 Approaches used to work with Brenda

5.10 Analysed using the practice and research basis for working with people who self-neglect, the following themes emerge in approaches used to work with Brenda.

5.11 The Individual. Empathetic and person-centred, relationship-based approaches do not appear to be a feature of work with Brenda. Her only input was a weekly visit from community nurses. It appears that the nurses had a good relationship with Brenda but the level of rapport to enable gentle persistence and more in-depth questioning of Brenda's reasons for refusals and family estrangement does not appear to have developed. The nurses recognised that there were risks and were eager to help Brenda. They shared information with other agencies on a basis other than consent, but respected Brenda's wish not to have her son contacted. No personal history is recorded for Brenda. This might have been collected as part of the awaited Care Act Assessment. The agencies involved did not offer advocacy, which would have been good practice to promote Brenda's engagement with services. There was no formal consideration of mental capacity or executive capacity recorded.

5.12 The Team around the adult. There was no reference to Swindon's Self-Neglect policy in deciding how best to help Brenda. The policy had recently been revised but was yet to be formally approved. There was limited inter-agency communication especially between the community nurses, who were present with, Brenda and ASC about the closure of the safeguarding concern, referral to and the waiting times for the Initial Contact Team and other response options. Communication was by email which was not robust enough to secure outcomes. No multi-agency meeting took place to share information, evaluate risk and agree plans. As a result, there was insufficient collaboration between agencies. The Initial Contact Team became the lead agency despite being clear that there was a two-to-three week waiting time for their input. In the absence of urgent action by the Initial Contact Team, it fell to community nurses who requested support and were not able to manage the risks alone. Brenda's reassurances were accepted above the concerns of the community nurses who were working with her. ASC's operations appear to have worked in a siloed way at this time, which ASC recognised and responded to by remodelling the roles of teams.

5.13 Although Brenda had told the adult safeguarding team on 15/01/21 that she would accept help, this was not borne out when other agencies attempted to help her or to seek help for her, including the ambulance service on 28/01/21 and the social care emergency duty service on 29/01/21.

5.14 The adult safeguarding team did not consider that the safeguarding concern raised on 14/01/21 met the criteria for a section 42 safeguarding enquiry on the basis that Brenda was "engaging with support and did not decline intervention". In hindsight, a safeguarding enquiry, under either Section 42 or on a non-statutory basis, may have helped in deciding whether any further action should have been taken to protect Brenda from harm due to the disparity between the evidence provided by the nurses of the risks and Brenda's reassurances that she could manage on her own. Community nurses could also have carried out their own assessment of the risks and escalated their concerns within their own organisation and within ASC. A new safeguarding policy and escalation policy has since been introduced in response to this.

5.15 The community nurses appear to have required some guidance on applying the Mental Capacity Act 2005 and particularly on deciding when a mental capacity assessment was necessary as no capacity assessment was completed on 14/01/21 or on 21/01/21, despite recording that Brenda did not understand the risks she faced. Some expert mental health advice may also have been helpful. There was an active response from the surgery ACP on 29/1/21 but this was not able to source further help for Brenda.

5.16 There may not have been sufficient management direction. The community nurses do not appear to have been advised to resubmit a safeguarding concern when the concern raised on 14/01/21 had not resulted in the provision of support for Brenda or to escalate their concerns to senior managers. The community nurses' manager was not aware that a safeguarding concern could be raised again. This suggests the need for greater awareness of safeguarding processes.

5.17 There was also sufficient management involvement in, and oversight of, how incoming work in the Initial Contact Team was being managed safely, was tracked across teams and how waiting lists were prioritised in ASC. There is limited evidence of line manager recording and guidance. This suggests a need for a process change which includes managerial decision making in the prioritisation and allocation of cases. This has been implemented by ASC during the process of this review.

5.18 A social care provider could have been commissioned to undertake welfare calls to support Brenda with food preparation and personal care before a Care Act assessment had been made (under section 19). Resistance is not unusual in older people needing services for the first time. They may been embarrassed about needing help and might be uncertain about what the involvement of services in their lives will mean and what to expect. Experienced care staff might have been introduced incrementally to try to build a trusting relationship with Brenda before an emergency situation developed. An agreement with a care agency to do this has since been agreed.

5.19 ADASS Guidance key themes

5.20 **Developing person centred approaches**. The relationship between Brenda had the community nurses did not demonstrate a rapport that could lead to exploration of what lay behind Brenda's presentation in January 2021. There was some trust as Brenda allowed the nurses to help her in some ways but the nursing role was to provide an Eprex injection and Brenda did not appear to expect more. For example, Brenda was surprised to be visited on 2/2/21 outside the regular Thursday calls, although she was seriously ill. There was little background information about Brenda recorded which might have provided a context within which to understand Brenda's worsening condition or estrangement from her family at a time when their input might have been useful. While community nurses were persistent in offering to facilitate outside support, their visits were once a week. No multi-agency discussions took place about increasing the frequency of the visits in response to the level of risk and its possible impact on Brenda's health. The community nurse records did not document a level of respectful challenge to Brenda, which is often needed to negotiate change.

5.21 **Multi-agency work is essential.** Joint work between the key agencies of ASC and community nursing was not strong. Brenda's situation would have benefitted from group problem solving and shared expertise about dilemmas (for example in balancing the duty to support autonomy with the duty to protect her life) and finding and allocating resources which might have been achieved through multi-agency meetings, under adult safeguarding processes or the Self-Neglect policy.

5.22 **Strong risk assessments**. No risk assessments considering likelihood, impact and mitigating factors or management plans were completed. Information was not always consistent. Euphemisms sometimes blurred the picture and reduced the sense of urgency. Strong risk assessments may have helped in communication with ASC and in escalating the need for action. The repeating pattern of events, including Brenda's reassurances, was not recognised, frustrating efforts to obtain support for Brenda.

5.23 **Professional Curiosity.** Brenda's presentation and statements were often taken at face value (for example, her reassurances that she could manage, or that her family "does not care" about her). Further explanations and evidence was not sought when there was contradictory information.

5.24 **Legal Literacy and application of Law**

5.25 There was no application of the Care Act 2014 or a proper assessment of capacity under the Mental Capacity Act 2005 until 2/2/21, although there were records about, and assumptions, of capacity.

6. PRACTICE AND CONTEXTUAL FACTORS

6.1 Demand management and austerity

6.2 The need to manage demand and to ration services in response to financial constraints may have impacted on perceptions of Brenda's social care needs. Self-reports by Brenda of not wanting or needing social care support were accepted despite the concerns of health staff working with her and the pre-assessment process was not used. Brenda was transferred by the safeguarding team to the Initial Contact Team, which was consistent with the self-neglect policy, but ICT home visits were being rationed at the time and had a waiting list.

Following Brenda’s death, screening staff in the safeguarding team have received additional legal training and the safeguarding team has been made aware of the pre-assessment process whereby a care service can be put in place before a Care Act assessment has been made and the process for this has been agreed with service brokers.

6.3 Workflows across ASC teams were not seamless. Brenda’s case lacked ownership and there did not seem to be an arrangement for tracking, escalating urgent need or keeping referrers informed. Communication between teams and managers was often by email where a conversation was needed instead. These issues were identified soon after Brenda’s death and measures were put in place for manager meetings, team remodelling and a new case recording system to improve communication.

6.4 **Impact of Covid 19:**

6.5 Covid restrictions were in place in January 2021 in response to the second wave of the coronavirus pandemic and these led to changes in work practices in ASC. The Initial Contact Team had donated staff resources to the hospital social work team and its capacity was further restricted by staff sickness.

6.6 As a result, Initial Contact Team home visits were restricted and there was a waiting list of two-to-three weeks. No one from ASC saw Brenda until 2/2/21 at which point her high-risk situation and lack of capacity were confirmed.

6.7 Brenda was concerned about Covid exposure, although she refused the vaccine. It is not known if these concerns influenced her refusal of outside help.

7 SUMMARY OF THEMES

7.1 A number of factors emerge which are associated with poor outcomes identified in research, guidance and previous SARs featuring self-neglect.

7.2 **Brenda’s Mental and physical health.** Brenda received minimal support with her mental health needs, which may have needed more monitoring. Brenda’s presentation was believed to be due to depression, hence she may have benefitted from a review of her treatment. As she was virtually housebound and alone Brenda’s psycho-social needs resulting from isolation could have been considered at an earlier stage. Brenda’s physical health needs, including undiagnosed cirrhosis of the liver, could also have impacted on her mood by causing fatigue.

7.3 **Self-Neglect procedures not referred to.** Brenda was identified as self-neglecting, with no reference to the self-neglect policy and procedure hence there was no interagency or best practice framework to inform work with Brenda and between services. Prior to this review, the need to embed training in practice was recognised as a priority and a staff survey was undertaken on the obstacles to working with people who self-neglect. The outcome of this will be used to inform future policy and procedural revisions.

7.4 **Lack of Person-Centred Work.** This did not appear to have been central to the community nurses’ role and there was not the rapport with Brenda to enable the nurses to gain trust

and negotiate when Brenda's situation worsened. The nurses, however, did raise concerns about Brenda and tried to obtain services for her. They did not explore Brenda's reasons for self-neglecting and this hampered their ability to help and to speak up for her.

7.5 **Multi-agency "team around the person" work was not effective.** The agencies worked in silos and did not communicate effectively. Information from health was not systematic enough to alert ASC to the need to prioritise Brenda and ASC did not seek to clarify Brenda's needs with the nurses, or between its own teams. The benefits of shared expertise dealing with the dilemmas and complexities and joint problem-solving were not available for Brenda. The services had no escalation routes to highlight risk when it appeared that Brenda was stalled in the system and at risk. The culture of collaboration and giving weight to other professional's concerns was not well developed on this occasion.

7.6 At an organisational level there was a lack of flexibility. ASC did not seem able to respond quickly to a person with multiple unmet needs and who was at risk of deteriorating further. This is not an uncommon presentation among older adults with sudden deterioration in self-care. There was not the flexibility in role for community nurses to respond either to Brenda mental health needs or to meet her basic needs of nutrition and incontinence. Instead weekly medication visits were maintained. Managers did not have enough oversight of the issues highlighted. The community nurses did not seem to have an escalation route to a senior ASC decision maker after their efforts to raise a concern about Brenda had not met with a timely response**.**

7.7 Strong risk assessments were not completed. There did not appear to be a practice of completing formal risk assessments. This left recording and communication incomplete and subjective, with no shared language and hence was less powerful in driving the need for action. This contributed to starting afresh with each contact about Brenda.

7.8 **An overarching theme is the need for more professional curiosity.** There were assumptions made without sufficient investigation. The community nurses did not explore reasons why Brenda did not accept outside or family involvement and assumed that Brenda's decisions were capacitous. ASC did not look into what was happening in Brenda's home and to Brenda. The safeguarding team did not make an enquiry after Brenda's telephone presentation seemed to contradict the nurse's concerns. Brenda's word was taken at face value on several occasions despite indications to the contrary. Although the safeguarding team had assessed Brenda as being willing to accept care, when this was handed over to the Initial Contact Team the urgency of the situation appears to have been lost.

7.9 Application of the Care Act 2014 several relevant powers and duties under the Care Act were not used for Brenda's safety and well-being. She had no offer of advocacy to help her engage and have a voice, she did not receive Section 19, pre-assessment services, nor an assessment of need. Section 42 Safeguarding was not used to make enquiries, bring agencies together and make Brenda safer. Health professionals may not know of these elements of the Act.

7.10 The Mental Capacity Act 2005 and Autonomy versus Duty of Care. The processes in the Code of Practice for the Mental Capacity Act were not used to undertake an assessment of Brenda's capacity to make decisions about remaining in an unsafe situation without essential services. There were comments about capacity in community nurse records but Brenda's inability to understand the risks of her decisions were not pursued. This was not challenged

by ASC until an Initial Contact Team social worker visited Brenda on 2/02/21. There was more emphasis on Brenda's autonomy than on her need for protection from harm and unwise decisions were not seen as part of a pattern.

8 CONCLUSIONS

8.1 The events considered in this SAR took place between Christmas Eve 2020 and 3/02/21. Community nurses recognised that Brenda had unmet care needs and appeared to be self-neglecting and raised a safeguarding concern about her to ASC on 14/01/21. This was a short time scale in which to form an understanding of, and respond to, Brenda's needs. The conclusions of this review should be considered within this context. The fifteen working days between the safeguarding concern and Brenda s death also emphasise the need to recognise the situations that require an urgent response and to prioritise resources and to intervene within a short time scale.

8.2 Safeguarding responses

8.3 A safeguarding concern was raised because Brenda's self-neglect had reached, in the vague words of a community nurse, a "threshold of risk". The safeguarding concern about Brenda, however, was closed and passed to the Initial Contact Team. The reasoning for this was that Brenda, when contacted by the adult safeguarding screener on 15/01/21, said that she was finding it more difficult to manage due to a deterioration in her health. According to the screener, Brenda presented as extremely lucid with a lovely sense of humour. Brenda appeared to have mental capacity (to make which decisions was not recorded) and no formal assessment of Brenda's mental capacity was made at the time.

8.4 Brenda agreed that a social worker would contact her and was advised that arrangements would be made for someone to visit or to telephone her to arrange care. Brenda's request was that she would prefer a female who "wasn't too bossy". The screener concluded that Brenda required care at home, which would maintain her independence. The screener notified the community nurse who had raised the concern, of the outcome of the telephone call. Brenda required an assessment under the Care Act, after which the appropriate care would be provided. The safeguarding team could arrange care and so Brenda was referred to the Initial Contact Team, which could.

8.5 When notified later that day that the Initial Contact Team would not visit unless there was very high risk, the safeguarding team screener considered that, based on the telephone conversation with Brenda, a telephone appointment to arrange care would be appropriate.

8.6 No attempt seems to have been made to raise awareness of the level of risk or the urgency of assessing and meeting Brenda's care needs. According to practitioners, the level of urgency was not understood. The safeguarding concern, however, identified that, "…the last time Brenda ate was a week ago, food was mouldy in the sink and there were bottles of out of date milk. She did not appear to know what day it was and there were faeces all around the toilet. Brenda also had a duvet in a black bag that appeared to have been soiled and was very protective of this and would not let us check this. She has declined any assistance on many occasions saying this is how she is and she will get better in her own time and do it in her own way. We checked her medication and it did not appear she had been taking her antidepressants. We contacted GP surgery to make them aware although Brenda was not

happy for us to do so. We feel her self-neglect is reaching a level of risk. We explained to Brenda that we were concerned and that we felt we needed to escalate this and Brenda was adamant that she did not want us to do so. Although Brenda has capacity to consent we do not feel she is aware of the level of risk potentially". This may suggest quite significant risks and on reflection, the safeguarding team recognised that the Initial Contact Team should have been contacted again. The Initial Contact Team confirmed that it would have passed Brenda to the Emergency Response Team if the level of urgency and of risk had been understood.

8.7 On 21/01/21, the safeguarding team screener was notified by the Initial Contact Team that there would be a two to three week wait for the assessment and notified the community nurse of this. However, on 22/01/21, the screener read a case note stating that Brenda was with the pre-assessment team. Whilst on the Initial Contact Team waiting list, a case note recorded that Brenda no longer wanted support and did not want to see anyone. Brenda was annoyed that she was receiving telephone calls from services. The safeguarding team recognised in hindsight that if Brenda had not appeared to accept support, and if it was aware of this, then a member of the team would have been visited her.

8.8 No further safeguarding concerns were raised despite the deterioration in Brenda's condition. A further safeguarding concern or escalation of the first one to more senior managers may have prompted inter-agency work. The referrer's manager does not appear to have believed this was possible when no other progress was made by ASC. A written risk assessment may have been useful in communicating the extent of the concerns about Brenda.

8.9 The Self-Neglect policy in Swindon was not, according to the Initial Contact Team, finalised and did not provide sufficient guidance on assessing urgency and risk. The policy has since been revised but does provide detailed guidance on joint management by the safeguarding team and other adult social care teams. From the perspective of the Safeguarding Team, cases involving domestic abuse or severe self-neglect would often lead to a visit form a member of the team but Brenda had been clear that she was willing to engage with services and accept support. In the view of practitioners, a safeguarding response would have added a layer of duplication within the assessment process.

8.10 An Adult Multi-Agency Safeguarding Hub has been introduced in Swindon, which is improving timely feedback to people who have raised safeguarding concerns about safeguarding actions.

8.11 **Care Act Assessment and ASC response**

8.12 Brenda had needs under most eligibility domains of the Care Act 2014. These were vital needs that if unmet would pose a danger to her health. Brenda had insufficient food and fluid intake and unmanaged incontinence causing there to be faeces on home surfaces, clothes, skin and bedding. Brenda was incorrectly deemed appropriate for a telephone assessment by the Initial Contact Team, contrary to good practice with self-neglect. Brenda's risks were not identified from the safeguarding alert and Brenda was placed on a waiting list when she needed immediate attention. When referrals were made to Rapid Response there was no outcome. The ASC response raises organisational issues where a referral for an older person in immediate need can be stalled in the ASC system and passed between teams and where important communication was sent by email instead of speaking in person. Advocacy support may have helped Brenda to engage but this was not offered from the beginning by

ASC. Brenda was referred on 14/1/21 and received no service up to 2/2/21 when she was admitted to hospital.

8.13 **Physical and mental health needs**

8.14 Brenda had a number of long-term health conditions, some of which caused fatigue and could interact with her long-standing depression. Brenda had undiagnosed cirrhosis of the liver. She was very isolated which was likely to further exacerbate depression and had also stopped her anti-depressants. Psycho-social interventions, befriending and similar may have helped. Brenda was not offered additional support with her mental health, even when it was thought to be the cause of her severe presentation. The Older Person's mental health team may have been able to advise if asked. Brenda had not seen a GP for over a year and Brenda refused contact with her GP. As Brenda deteriorated and became immobile, her poor food and fluid intake plus unmanaged incontinence were a risk to skin integrity. There is no evidence that an incontinence service was considered. Brenda's skin was not examined until 2/2/21 when she had ulcers on her body. Brenda's reluctance required gentle assertiveness in view of potential harm. Nurses did contact her GP and ASC without Brenda's consent and clearly wanted to support her. However, the community nurses and their managers did not increase the frequency of home visits from weekly or the scope of the nursing role until other services were in place. After 14/1/21 Brenda was not able to meet her needs over seven days on her own. The community nursing role did not seem to be wide enough in scope or have the flexibility to respond to Brenda's situation of becoming depressed, withdrawn from life and physically ill. On 28/1/21 the ambulance crew were focussed on Brenda's self-neglect and refusal of help. It is not known how ill Brenda was then, but within five days Brenda was admitted to hospital near death.

8.15 **Inter-agency communication and collaboration did not take place**.

8.16 The difficulties with Brenda's referral to ASC are examples of failures in inter-agency working and a possible lack of giving due weight to health professionals' concerns. Apart from safeguarding, when the issue of self-neglect was considered to be at the centre of Brenda's situation, the existing self-neglect procedures also recommended inter-agency collaboration, information sharing and joint problem solving with shared expertise. This did not happen and hampered the response to Brenda's needs. Sharing information and discussion in a meeting would have clarified Brenda's self-reports as unreliable. There was no escalation by managers in ASC and in community nursing. The information provided by community nurses did not include formal assessments of risk or of capacity. Both of these issues were referred to in vague and sometimes subjective terms. Robust assessments on both issues would have supported decision makers in ASC where there were some ambiguities, such as Brenda's choices and whether she could manage as she insisted.

8.17 **Risk assessment**

8.18 The lack of risk assessment was significant in not prompting action by ASC. Risk assessments are expected practice in nursing and social care and in institutional settings. Working in Brenda's own home, community nurses seemed to work without risk assessment guidance or the concept of a template to record the risks they tried to raise with others. Formal risk assessment would have provided an objective record in place of speculation and potential bias. It would have named each risk and a consideration of what could happen as a consequence. The risk assessment process would have included evaluation of severity and what might mitigate the negative impacts. Risk assessments include escalation steps and would lay out the potential interaction of risks, such as on skin integrity. Such a document would be evidence based and establish a common language and understanding across staff and agencies. Risks instead were open to re-interpretation, vague language and minimising and not clear statement of action taken and action needed. All agencies underestimated risk resulting in missed opportunities to intervene by ASC, GP, ambulance and the nursing service despite the latter having eyes on Brenda's situation.

8.19 **Person Centred approaches were not used**

8.20 There appeared to be a lack of empathy with Brenda across agencies. Descriptions of her situation often dwelt on the state of her home and did not focus on what was happening for Brenda. The system appears to have lost sight of Brenda as a person. Eileen Munro recommended moving from bureaucratic approaches in social care to relationship-based work with people at risk. Although writing about social work with children, her message has application to all social work and lay behind a large-scale reform of social work (The Munro Review of Child Protection TSO 2011 E Munro).

8.21 Relationship based work is not limited to social work and is needed in nursing. The 2016 Kings Fund report, "Understanding quality in district nursing services", for example, emphasises the need to care for the whole person rather than just to be task focused. Holistic, person-centred, strengths-based approaches are a requirement of the Nursing and Midwifery Council's 2022 "Standards of Proficiency for community nursing specialist practice qualifications". They are also part of the registration standards of the Care Quality Commission, which require that community nursing services are safe, effective, caring, responsive to people's needs and well-led. The CQC highlights in inspection reports (including for Great Western Hospital NHS Foundation Trust) that the requirements of the standard for caring include compassion and emotional support for patients.

8.22 Brenda was eating so little that she had become noticeably shrunken by 28/1/21. All the aspects of her presentation were not pieced together to form a holistic overview. No personal history appears to have been taken so Brenda was not seen in the context of a long life lived with interests, achievements and preferences. Only Brenda's problems were focused on and there were no conversations to find strength-based solutions. Hence Brenda was not asked what lay behind her worsening presentation, what she was thinking and feeling and whether she was in pain or fear? There was a lack of professional curiosity about what lay behind Brenda's condition. She had never deteriorated before to this extent, so exploration with her of what had happened and why was she was so resistant to outside help was required. A clothes wash was put in the washing machine on 21/1/21 with no visit due for a week and Brenda's word was accepted that she could sort out the wet washing. Gentle assertiveness was needed by this point and had been used on occasions (cleaning up after incontinence for example) but not consistently.

8.23 Key elements of the context in which effective practice with people who self-neglect can take place include, according to Michael Preston-Shoot and Suzy Braye, where:

- Agencies share definitions and understanding of self-neglect.
- Interagency coordination and shared risk-management is facilitated by clear referral routes, communication and decision-making systems.
- Longer-term supportive, relationship-based involvement is accepted as a pattern of work.
- Training and supervision challenge and support practitioners to engage with the ethical challenges, legal options, skills and emotions involved in self-neglect practice

8.24 Organisational and managerial support is required to enable practitioners to have the time and resources to deliver holistic, person-centred, strength-based compassionate care. Time and resources are, however, often limited and task rather than relationship focused approaches can seem superficially to be more productive. There is a need locally to consider how the relationship-based approaches that might have been helpful to understand how Brenda could be better supported.

8.25 Work around recognising self-neglect has been carried out and a self-neglect template for practitioners is being implemented.

8.26 The community nurses had a good working relationship to contact Brenda GP if they required additional help or advice and following a request for more support, the ACP visited Brenda. The ACP said that it was obvious that Brenda was self-neglecting.

8.27 The ACP has a developed a vulnerability MDT which launched in January 2022. This meets fortnightly and consists of the ACP as the safeguarding lead, a lead nurse, with a mental health background, a GP, a social prescriber, the frailty ACP and a pharmacist. The vulnerability MDT considers the patients with complex needs like Brenda and is seeking a wider membership.

8.28 **Contact with Family**

8.29 Little is known about Brenda's family and the reasons for her refusal of contact with her son were not explored. The reasons why Brenda did not want contact with her son might have been managed with tact, especially in view of how serious Brenda's condition was. Brenda's son was offered the opportunity to speak with the safeguarding review writer but asked only to see a copy of the final report. Not having any family contact on record is of concern and meant that Brenda's son could not be told of Brenda's hospital admittance on 2/2/21. Brenda was asked, but refused, to share her son's telephone number. Family involvement may have been helpful considering that Brenda appears to have thought that they did not care.

8.30 A community nurse offered to speak to Brenda's son on 21/01/21 but Brenda "adamantly declined" this.

8.5 **Advocacy**

8.6 If practitioners felt unable to take on a person-centred approach and could not involve Brenda's family, an advocate was essential and yet was not mentioned in health or ASC records. The advocate could have helped Brenda engage, find out about her wishes and concerns and give her a voice.

8.31 Self-neglect and best practice

8.32 Brenda's condition was frequently referred to as self-neglect but appears to have been considered to be a lifestyle choice. Despite the difficulty and dilemmas of trying to support Brenda, no reference was made to self-neglect procedures or guidance in nursing or ASC records. Work with Brenda did not reflect the three key themes identified by ADASS for good practice of: person centred practice, good inter-agency working and strong risk assessments. The label of self-neglect brought Brenda no benefit and may have taken focus and empathy away from her as an isolated 75-year-old woman with poor health, serious depression and having taken to her bed. Brenda was alone with no services to meet the most basic needs apart from a weekly visit by a community nurse. Awareness of self-neglect, policies, procedures and guidance has been the topic of staff survey following Brenda's death.

8.33 Practitioners agreed that a collective understanding of self-neglect and a shared means of communicating objectively about its extent was required. It is also not always clear if someone is being neglected or is self-neglecting. Brenda deteriorated very quickly and practitioners in the Initial Contact and Safeguarding Teams considered that there was confusion at the time over whether Brenda was self-neglecting or being neglected due to her needs not being recognised and met.

8.34 Determining between neglect and self-neglect often involves a judgement which might be summarised as determining whether the person is, "willing but unable, or able but unwilling". At times, Brenda said that she was not able to meet her own needs and would accept support, whilst at other times she denied that she needed support and refused to accept it. It is important to note that "willingness" and "unwillingness" in this context should not be ascribed to lifestyle choice. There are many factors that may affect a person's willingness or motivation to do things, including mental and physical health conditions.

8.35 Practitioners in the Initial Contact and Safeguarding Teams recognised that Brenda has a long history of depression. This may have impacted on her ability to care for herself and to accept support but was not followed up because of the frequently positive nature of their telephone contacts with her.

8.36 The social worker from the Initial Contact Team whose visit to Brenda on 02/02/21 led to her admission to hospital said that Brenda was lying on the settee covered by a sheet. The social worker and the district nurse removed the sheet with Brenda's permission and the social worker told the safeguarding adults review writer that Brenda had sores like she had never seen before. Brenda had distended stomach and covered in faeces but was adamant that she did not want help.

8.37 Role of community Nurses

The role of the community nurses and their ability to identify problems early and apply professional curiosity outside of assigned tasks is an important one and may require more empowerment and flexibility. Community nurses work with many isolated older people with multiple health needs and often co-existing mental health needs, which can make them vulnerable to rapid deterioration, especially when isolated with no support.

8.38 Mental Capacity Assessment

8.39 The Mental Capacity Act 2005 continues to be problematic in application despite training programmes and a Code of Practice. Brenda was known to have depression which was worsening. As Brenda's unwise decisions to refuse support continued and were causing her harm and a formal and recorded Mental Capacity assessment should have been undertaken by the community nurses. There was confusion about which decisions to assess and unsureness about the process and what questions to ask. Identifying repeating patterns and taking a long, not a snapshot, view of capacity does not seem to have been considered.

8.40 Over time it is clear that the nurses believed Brenda could not weigh up information because she did not understand the risks she was facing but this was not recorded as a clear finding that Brenda was unable to make decisions about her health and care needs. In combination with Brenda's impairment in the functioning of her mind and brain, in the form, for example, of now untreated depression, this may have meant that Brenda lacked the capacity to make decisions about her health and care needs at that time. A finding of incapacity means that there is the power and duty to start a best interests process. This could have brought together ASC, health and family or an advocate as well as Brenda. This could have empowered practitioners to, for example, introduce carers incrementally to build up rapport and trust using experienced care staff who were familiar with working in this way. Ambiguity about mental capacity created confusion and delay about what must be done. Brenda may have lacked the executive capacity to put decisions into action.

8.41 The social worker from the Initial Contact Team who visited Brenda on 02/02/21, used the immediate evidence of Brenda's self-neglect to inform the mental capacity assessment which led to Brenda being taken to hospital. The social worker compared Brenda's answers to simple questions such as, "what have you eaten today?" with the evidence that food was liquefying in unopened carrier bags and lack of evidence of the presence of edible food of any signs of even simple meal preparation. Whilst Brenda gave cogent answers there was no evidence to support these.

8.42 The proposed revised Code of Practice for the Mental Capacity Act will, subject to consultation, clarify the assessment process and when capacity should be assessed. It also proposes 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 revised Code of Practice also proposes a statement 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 of the proposed Code of Practice for the Mental Capacity Act).

8.43 Impact of Covid

8.44 Restrictions due to Covid-19 were in place and had reduced the capacity of the Initial Contact Team and may have influenced some working practices including the decision to restrict in-person assessments. Telephone assessments are not suitable to engage people

who self-neglect. The experience of Brenda's false reassurances illustrates the need for rapport, trust and gentle challenge. This and Brenda not being prioritised may have prevented Brenda having an assessment Brenda's concerns about Covid 19 may have influenced her refusal of outside support.

9 GOOD PRACTICE

9.1 The actions by the social worker, ACP and community nurse on 2nd February 2022 resulted in Brenda's admission to hospital and are likely to have prevented her from dying alone at home. Most significant of these actions was the mental capacity assessment which compared Brenda's answers to questions about her self-care and nutrition with the visual evidence of Brenda's self-neglect. Whilst Brenda gave cogent answers there was no evidence to support these and therefore the social worker concluded that Brenda lacked the mental capacity to keep herself safe. This is an example of good practice in mental capacity assessment.

10 ACTIONS ALREADY TAKEN

10.1 It is important that agencies do not wait until the safeguarding adults review process has been completed before they identify and making changes to practice, policy, procedure, guidance or training. Other published SARs on similar topics can also be helpful sources of information on changes that can be made.

10.2 Since Brenda's death, ASC has carried out a number of actions and has made changes to strengthen its workflows and to improve areas of practice including screening, case tracking across teams, prioritisation of cases, case closure and contacting referrers. These include:

10.3 Safeguarding processes were reviewed immediately after the death of Brenda and a number of improvements were made in July 21. New practice guidance was developed and is now stored on main adult social care intranet. This includes guidance on transferring cases to other teams (How to safely transfer cases).

10.4 In August 2020 a new Quality Assurance service was developed to strengthen the processes in Adult Services. Team Managers now complete monthly case file audits that include talking to the person who has experience of using the service.

10.5 Case file audits are scrutinised at a Quality Assurance clinic and a quality rating is applied, this rating is added to a broader team performance report for further scrutiny before being shared at the new style Adult Quality Assurance and Performance Board.

10.6 Surveys were sent out to ensure that teams were aware of the practice guidance and 80% of people reported that the guidance had led to improvements in their practice.

10.7 A review of the application of this guidance is due to take place in April 2022.

10.8 The prioritisation of ICT cases is managed outside of the Eclipse Case Management System and is held in Share Point. The prioritisation list is overseen by a Service Manager, there is evidence of appropriate escalation when needed.

10.9 A review of the prioritisation list to take place in April 2022, led by the Head of Service.

10.10 Audits of safeguarding alerts that were closed without enquiries of were completed by an independent audit lead, learning was identified and had been incorporated into an ongoing service improvement plan.

10.11 An escalation process has been developed and agreed so that fresh referrals can be made if the risk persists or increases after a case has been closed with or without safeguarding action.

10.12 A risk assessment methodology and recording tool has been created in the safeguarding policy to identify the likelihood and impact of each risk, and the person's attitude to the risk, whether the MCA applies, whether there is mitigation in place or escalation is required.

10.13 Weekly Safeguarding Huddle meetings are held between ICT and URT.

10.14 All teams are aware that pre-assessment can be used to support people basic needs not met

11. RECOMMENDATIONS

11.1 Building on these changes, the following recommendations are made, divided into single and multi-agency action

11.2 Single Agency Actions:

11.3 **RECOMMENDATION 1:** GP Surgeries should review patients coded with "severe frailty" annually and create a care plan which includes actions if there is rapid deterioration. These adults can be identified using the "electronic frailty index", which uses data available in the GP electronic health records to identify and severity grade frailty. This enables the identification of older people who are fit, and those with mild, moderate and severe frailty. GP surgeries should ensure that they follow these processes.

11.4 **RECOMMENDATION 2:** Community Nurse health risk assessments should be made for people coded as of high frailty who are living in their own homes and where there are risks such as skin integrity, incontinence, very low food or fluid intake. The presence of these factors can indicate the need for a multi-agency approach

11.5 Multi-agency actions

11.6 **RECOMMENDATION 3:** The SSP through the PDG should ensure there is multi-agency training available to all staff that promotes strength-based approaches to working with individuals who are considered to be self-neglecting.

11.7 **RECOMMENDATION 4:** The SSP should seek assurance that the organisations involved on this review are raising awareness of key elements of the Care Act 2014 (especially as highlighted by this report: assessment, representation, the wellbeing principle, Section 19) amongst their staff using mechanisms such as supervision and professional development.

11.8 **RECOMMENDATION 5:** The SSP should seek assurance that all organisations involved in this review are auditing the knowledge and skills of their staff on the Mental Capacity Act, including executive capacity using mechanisms such as supervision and professional development.

11.9 **RECOMMENDATION 6:** The SSP should seek assurance that all organisations involved in this review have effective safeguarding supervision arrangements in place including safeguarding supervision where escalation and acting on a basis other than consent can be considered and actions agreed.

11.10 **RECOMMENDATION 7:** The SSP should review how the process in the self-neglect policy for multi-agency meetings, where there are concerns that a client may decline care despite their high level of need, is applied. A further practitioner survey could be used to determine if there has been a change since the last practitioner survey completed as part of this review.