West Sussex
Safeguarding Adults
Board
Making Safeguarding Personal

Safeguarding Adults Review (SAR) in respect of Jean Willis

Date of birth- 25th August 1936
Date of death- 12th August 2019

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1. Foreword

The West Sussex Safeguarding Adults Board (the Board) has published a Safeguarding Adults Review (SAR) that looked into the circumstances in the lead up to the death of Jean Willis.

The Board and the Independent Reviewer express their sincere condolences to the family and friends of Jean. The family have met with the Reviewer and, have contributed to this Review. In order to ensure that Jean's voice is heard, and with the agreement of her family, Jeans' name has been used in full in this Review.

The purpose of a Safeguarding Adults Review is not to reinvestigate or to apportion blame but to establish where and, how lessons can be learned, and services improved for all those who use them and, for their families and carers.

This Review looks at the circumstances and the support offered in the lead up to Jean's death and, examines the actions of various agencies that were involved in order to reduce the likelihood of similar events happening again, in the future. Recommendations have been made as a result of this Review, which will enable lessons to be learned and, will contribute to service development and improvement.

The Review identified four key findings. In summary these are: missed opportunities for the coordination of care, a lack of multi-agency approaches, limited evidence that Jean's wishes and feelings had been considered and, a lack of coordinated response to Jean's deteriorating health.

The Board and the SAR Subgroup, which reports to the Board, will monitor progress on the implementation of all recommendations through receiving reports from all agencies involved in working Jean, that reflect progress on their continued action plan to reduce risk and ensure that the necessary development of systems and procedures continue to improve practice.

The Board will also ensure that the learning from this Review is widely disseminated and that the outcomes of the learning will lead to improved services in West Sussex.

Annie Callanan, Independent Chair

2. Legal Context

2.1. The Care Act 2014, Section 44, requires that Safeguarding Adults Boards must arrange a Safeguarding Adults Review when certain criteria are met.

2.2. These are:

- When an adult has died because of abuse or neglect, or has not died but experienced serious abuse or neglect, whether known or suspected, and;
- There is a concern that partner agencies could have worked more effectively to protect the adult.

2.3. Safeguarding Adults Reviews are required to reflect the six safeguarding adults' principles, as defined in the Care Act. These are empowerment, prevention, proportionality, protection, partnership, and accountability.

2.4. The aims of the Safeguarding Adults Review are to contribute to the improved safety and wellbeing of adults with care and support needs and, if possible, to provide a legacy and support family and friends.

2.5. There are clear review objectives which have been addressed to achieve these aims. Through a shared commitment to openness and reflective learning, involved agencies have sought to reach an understanding of the facts (what happened), an analysis and findings (what went wrong and what went right), the recommendations to improve services and to reduce the risk of repeat circumstances, and a shared action plan to implement these recommendations. It is not the purpose of the review to re-investigate the suspected abuse or neglect, or to apportion blame to any party.

2.6. The review process to meet these aims and objectives has followed a clear path. The Independent Reviewer has chaired an initial panel meeting to agree the review terms of reference; conducted research by critically analysing Individual Management Reports, chronologies and relevant records held by involved agencies and by interviewing representatives of agencies; culminating in a planned Safeguarding Adults Review Outcome panel meeting and presentation to the West Sussex Safeguarding Adults Board.

3. Introduction

3.1. Jean Willis was an 82-year-old woman who was a much-loved Mother and Grandmother. Jean had lived an interesting and fulfilled life. In the last few months of her life, she required 24-hour support provided in a care home. She had lived at the Care Home for 3 months.

3.2. Jean was admitted to Worthing hospital on 10th August 2019 after becoming increasingly unwell with a UTI, diarrhoea, weight loss, abdominal pain and pressure ulcers. She died on 12th August 2019. The cause of death on her medical certificate was stated as: Pyelonephritis leading to Severe Sepsis leading to multiple organ failure (leading to death). Other significant conditions contributing to the death but not related to the disease or condition causing it: Alzheimer's Dementia, Severely Frail.

3.3. A safeguarding referral was made by hospital staff due to concerns about neglect. A S42 Safeguarding enquiry was carried out and concluded that Jean "may have not received an adequate amount of health led input in the prior days to her being admitted to hospital. The care home may have needed to be more insistent with the health services due to not being able to manage her increasing care needs".

4. Rationale for carrying out a Safeguarding Adults Review

4.1. A SAR referral was made by West Sussex County Council (WSCC), on 25th October 2019 following her death in hospital.

4.2. On initial consideration of the referral in November 2019, it was agreed that based on the available information at that time, it did not meet the criteria for a SAR. However, the family asked for this decision to be reconsidered. On review of the case and further consideration, it was agreed in January 2021 that the criteria for a SAR was met. The information from family and that provided for the Section 42 Safeguarding enquiry indicated that agencies involved with Jean could have worked more effectively together with regards to safeguarding, risk assessment and care planning.

4.3. The West Sussex Safeguarding adult Board has a statutory duty to arrange a Safeguarding Adult Review (SAR) where:

- An adult with care and support needs has died and the SAB knows or suspects that the death resulted from abuse or neglect, or an adult is still alive, and the SAB knows or suspects that they have experienced serious abuse or neglect, and
- there is reasonable cause for concern about how the Board, its members or others worked together to safeguard the adult.

In addition to the above SABs might select cases for either of the reasons noted in the statutory guidance:

- Where a case can provide useful insights into the way organisations are working together to prevent and reduce abuse and neglect of adults.
- To explore examples of good practice where this is likely to identify lessons that can be applied to future cases.

4.4. The purpose of the SAR is to promote effective learning and improvement to prevent future deaths or serious harm occurring again. The aim is that lessons can be learned from the case and for those lessons to be applied to future cases to prevent similar harm re-occurring.

4.5. According to the SAR Protocol, if the SAR criteria is not met but the relevant SAB feels that there are lessons to be learnt, an alternative review may be undertaken.

4.6. 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 in the future. The purpose is not to allocate blame or responsibility but to identify ways of improving how agencies work, singly and together, to help and protect adults with care and support needs who are at risk of abuse and neglect, including self-neglect, and are unable to protect themselves.

4.7. The Independent Chair of the West Sussex Safeguarding adult Board agreed that the criteria for a Safeguarding Adult Review were met on 4th January 2021 on that grounds that that agencies involved with Jean could have worked more effectively together with regards to safeguarding, risk assessment and care planning. Additionally, that there were missed opportunities related to Jean's health needs which may have been a contributing factor to her earlier than expected death.

4.8. The Independent reviewer was confirmed on 26th January 2021 (Anna Berry).

4.9. The membership of the SAR panel comprised the members of the Board's SAR subgroup, with the addition of co-opted members representing the agencies which had provided services to Jean.

- Independent Reviewer, overview report writer, panel chair: Anna Berry
- West Sussex SAB Business Manager
- West Sussex County Council (WSCC)
- West Sussex Clinical Commissioning Group (CCG)
- Sussex Community NHS Foundation Trust (SCFT)
- Western Sussex Hospitals NHS Foundation Trust (WSFT)
- Sussex Police
- The GP Practice
- The Care Home

4.10. The SAR panel also received administrative support from the SAB senior data and support officer.

5. Review Process

Scope and focus of the SAR (Terms of Reference)

5.1. The key question to be addressed by the SAR was identified as follows: "There is a need to determine what gaps may have existed, gain an understanding of if/how agencies pre-empted arising risk and what multi-agency lessons could be learnt to minimise this situation reoccurring”. From this, the aims and areas for consideration within the scope of the review were:

- Generally, to improve the safety and wellbeing of adults at risk and for recommendations to be made to reduce the risk of similar safeguarding concerns occurring in the future.
- For agencies/organisations to work together in a spirit of openness, to gain an understanding of the facts, analyse the findings and produce recommendations and actions.
- Consider whether agencies/organisations: worked together effectively, had robust systems of referral and communication; shared information appropriately and evidenced good multi-agency working, planning, risk assessing, management and leadership with a particular focus on the planning and coordination of care.
- Identify whether any other interventions or processes might have improved the outcomes or experience of Jean. This should include the sharing of information to ensure appropriate support was in place to meet needs, with a consideration of the trajectory of dementia and advanced care planning required, including Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) aspects, involving both the adult and their family.
- Consider the impact of systemic issues, including operational pressures, culture, and the environment on decision-making, within and across the Multi-Agency partnership.
- Consider whether practice was in line with statutory and procedural requirements.
- Consider whether the safeguarding concerns were avoidable or preventable.
- Consider the support/information available to family members in communicating and understanding health and care needs, also the support available where the views of the carers about the best interests of residents differ to the family and cannot be reconciled by discussion.
- Reflect upon Jean’s needs and wishes and how these may have been listened to by those supporting her in the last months of her life, to include consideration as to whether any other interventions and/or processes may have improved her experience.

Methodology

5.2. A methodology was agreed that would recognise good practice and strengths that can be built on, as well as areas that require improvements. The process was agreed to be proportionate, collaborative, and analytical, actively engage all agencies/organisations involved and family members.

5.3. A bespoke panel was convened to oversee the process and individual chronologies were submitted by the agencies represented on the panel.

5.4. The time frame agreed was from 21st May 2019 (the date of admission to the Care Home) to 12th August 2019 (date of death)

5.5. When combined, the chronologies highlighted episodes of care. The admission to the care home and the opportunity for the family, GP, and care provider to work together, the period of significant deterioration whilst in the care home and the days leading up to hospitalisation when Jean died.

5.6. The transparency and reflections of the panel members, analysis of the chronologies and perspectives of the family members have facilitated a rounded view of events and practice.

6. Family Involvement

6.1. Family members had been in contact with Board Support Team and received contact from the Independent Chair in the months prior to the review commencing - all the information from those communications was made available to the Reviewer.

6.2. Jean's Son and Daughter have supplied several documents for the purpose of the Review and met (virtually) with the Lead Reviewer to gather information and invite comments and reflections on how agencies worked with Jean and with them.

6.3. Family members have also provided a number of reflections and multiple insights into Jean's life and personality. It is their wishes that Jean Willis's given name be used for this Review.

6.4. Family members strongly believe that there is meaningful learning that can be gained from reviewing Jean's case. This learning includes quality, coordination and planning of care, family support, communication, and assistance in navigating through health and social care systems. They hope that agencies will use this learning to improve practice.

7. About Jean

7.1. Jean's Son and Daughter have provided great insight into her life, personality, and interests. They do not want her to be defined by her final few months. They particularly highlighted her determination and resilience and summed this up in the following way:

7.2. "I think it is important to say that during this period, despite having to live with chronic back pain and disability, and with dementia relentlessly chipping away at her (which she was fully aware was robbing her of her mental faculties), Mum was resilient, and a lot of the time was able to call on immense inner reserves to get her through. She was an intelligent and determined person and our aim was to do as much as we could for her to enable her to continue with the best quality of life possible bearing in mind the circumstances that she now found herself in. She managed to maintain a sense of humour, even during the most difficult times".

7.3. Jean's family and friends describe her as a strong willed and determined lady who was devoted to her family and worked hard within her community in the Badger Trust raising money and working tirelessly for many years. Jean was very well known for her resourcefulness and her sense of humour and there are many memories that are held dear to those close to her.

7.4. Jean was a hard-working lady and had multiple jobs and roles when her children were growing up. Her friends and family set out in many ways the strength of her character, her sense of humour, her love of life, intelligence and they have many happy times and memories.

8. Background and narrative

8.1. Jean was diagnosed with dementia in 2017, she lived in her own home with increasing support from family until May 2019 when, following a short hospital admission she moved to the care home.

8.2. The home is described by the Care Quality Commission (CQC) as a 'care home' and provides accommodation for up to 20 people living with dementia. It was last inspected in 2017 and was rated as "good" across all the inspection areas.

8.3. Throughout 2018 Jean struggled to cope on a day-to-day basis due to dementia and additionally she became more physically disabled due to her degenerative back condition. At this point she required a wheelchair for trips out of the house.

8.4. Her family helped as much as they were able to, for example - taking care of her food shopping, keeping the house clean, keeping her company, taking her on outings, accompanying her to doctors' appointments, making sure that she was taking her daily medication and being on hand whenever she needed anything.

8.5. In April 2019, the family tried to secure the services of a home-care provider which unfortunately was unable to arrange the assistance that they had initially said they were able to offer.

8.6. In April 2019, the family requested a home visit by the GP due to concerns that she was unwell, antibiotics were prescribed but unfortunately Jean deteriorated and at the beginning of May 2019 was admitted to hospital where she was treated for a Urinary Tract Infection (UTI).

8.7. Jean was discharged home after one night and stayed with her son for three days. She had significantly deteriorated in terms of self-care skills and by the time she returned to her own home the family realised that they could not provide the level of care and safety that Jean now needed.

8.8. The family considered the different options and after researching local care homes and looking at CQC ratings they arranged a visit to the care home and accepted a ground floor room for Jean. This was an incredibly difficult decision for the family. She became a resident in the care home on 21st May 2019.

8.9. The immediate timeframe prior to Jean's move can be considered as an opportunity to have explored Jean's needs, to review her deteriorating dementia and disability and to offer support to the family who were coordinating care in Jean's best interests without the benefit of support.

8.10. It is important to note that this situation was not something the family were familiar with and they did not know how to navigate their way around the health and social care system. They did not know where and how to access support, nor were they aware of any assessment process that would explore Jean's social or healthcare needs or consider what she may have been entitled to receive. Jean's Son and Daughter did apply for Attendance Allowance, which was granted at the lower rate.

8.11. It has been considered but is difficult to conclude without hindsight bias that a formal assessment for continuing health care may have been indicated at this point however a referral was not made by any of the professionals involved and the family were not aware of this process and thus would not have known to enquire about that. This will be considered later in the review (Key practice episode 1)

8.12. During Jeans' time with the care home her main care providers were her GP and the District Nursing team. District Nurses visited weekly and when requested for pressure area assessment and care. The GP was contacted via telephone and also visited Jean in the home.

8.13. Reflected in the information are multiple conversations between the Registered Manager/care team, the District Nursing Team, and the GP. It is not entirely clear who was coordinating the multi-disciplinary care plan and the family found it difficult to navigate the communication consistently across these teams.

8.14. The question of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) was raised with the family shortly after admission. This was a very important decision for Jean and at that stage the family did not wish for this to be in place. This prompted the family to provide copies of the Lasting Power of Attorney documents to the care home and the GP (for both health and care, and money finances and property). There could have been an opportunity to use this conversation as a basis for the overall coordinated planning of care with the family and this will be explored later in the review (Key practice episode 2).

8.15. A DNACPR was subsequently put into place in August 2019.

8.16. It is reflected within the information from the care home, the GP and from discussions with the family that there was a breakdown in communication. There are different perspectives and accounts of some elements of this however, the result of this was that it became difficult for the family to feel fully informed.

8.17. The care home and the GP both reflect that the family visited regularly and there were lots of conversations with them at different times, however the multi-agency communication as a whole could have been strengthened to ensure that the family were fully informed of all aspects of care both in the care home and with the clinical management plan. The family reflect that the conversation were largely instigated by them asking questions about Jean's care.

8.18. The family were concerned that there was not always consistency in the staff looking after Jean and felt that people did not get to know her well or understand her needs. This raises some questions about the principle of person-centred care. The family cited concerns about quality and dignity, and they report that this distressed Jean. The extent to which Jean's wishes and feelings influenced her care planning will be considered later in the review (Key practice episode 3).

8.19. The family raise concerns that they knew that Jean was deteriorating and felt disempowered to act and excluded from decision making by the agencies involved in her care. They started to look at both residential and nursing homes for Jean in July/August 2019. The family were particularly looking for a home that provided specialist Dementia care and a safe environment that would provide all aspects of care to Jean. This was in the absence of a formal assessment which is discussed later in the review (Key practice episode 1).

8.20. The family became particularly concerned on between 6th- 10th August 2019 and there were several calls between the care home, the GP practice and the family ultimately resulting in Jean being taken by ambulance to hospital on 10th August. Jean's family had made the decision that they were going to call for an ambulance themselves if a clinical decision was not made to do so. The chronology provided by agencies demonstrate concern during this timeframe about deterioration that was expressed by the family and by the care home. The timeliness and decision making for Jean to be admitted to hospital does not resonate with this level of concern.

8.21. Jean was taken by ambulance to Worthing Hospital, on arrival it was noted that Jean had a cachectic appearance, pressure ulcer and moisture related skin damage. The DNACPR was already in place. The Emergency Department assessment also noted a 3-week history of diarrhoea and double incontinence prior to admission, a poor appetite and significant weight loss since May. The Consultant review confirmed an impression of severe sepsis, multi-organ failure, and pyelonephritis. Given the severity of Jean's presentation the plan was to treat with IV antibiotics and fluids if there was further deterioration to commence end of life care. A safeguarding referral was made to West Sussex County Council due to concerns about Jean's presentation and neglect. Jean died on 12th August 2019.

8.22. In the last few weeks of Jean's life there is concern expressed by the family, and in the later finding of the S42 enquiry about the timely coordination of health responses. This will be considered later in the review (Key practice Episode 4).

8.23. The chronology and panel discussions align with the family's timeline, the initial move to the care home, the emerging communication and coordination issues and the deterioration of Jean's health and timeliness of response. It is important to recognise that the family feel that Jean suffered unnecessarily in the days leading up to her death and this is somewhat supported by the S42 enquiry.

In summary the following key practice episodes will be considered:

- Decision making leading to Jean's admission to a care home (consideration of support or formal assessment)
- Coordination and oversight of care between services and family
- Considering Jean's wishes and daily lived experience- person centred care.
- Timely coordination and response to deterioration leading to Jean's death.

9. Analysis of Practice

Key Practice Episode 1

9.1. The focus of this episode considers the decision for Jean to move into a care home. This was a very difficult decisions for the family to make and the events leading up to this decision have been explored with the family.

9.2. At this point Jean's care was being provided by her GP, the District Nursing Service and hospital staff during a brief admission to hospital.

9.3. Outside of the timeframe for this review (2018) but to note, a dementia advisor from The Alzheimer's Society had visited the family which was extremely helpful at the point of diagnosis. Additionally, Jean was seen several times by a Dementia Nurse from the Memory Clinic.

9.4. At the point that the family started to be very concerned about Jean living alone in her own home, they made several enquiries about different options of care provision. They were not aware there was any form of assessment that would help them to understand the level of care that Jean needed and so researched care home options for Jean to self-fund.

9.5. The family are not experts in dementia care and were in the position where they had to decide themselves on what level of care Jean needed. They had to navigate their own way through the health and social care system. It is not evident that there was consideration by any agency to have Jean's primary health need assessed.

9.6. There was opportunity for any one of the agencies working with Jean to facilitate this prior to and at any stage of the time frame of this review.

9.7. A first step could have been to advise the family to request a "needs assessment" from West Sussex County Council. Although Jean may have not been entitled to anything more than the lower rate Attendance Allowance, it would have helped to ascertain the type of care that Jean needed. It could also have triggered a Continuing Health Care checklist.

9.8. NHS continuing healthcare funding is provided if you are considered to have a 'primary health need' for health care and as such Jean may then have been entitled to NHS fully funded CHC if a primary health need had been identified.

9.9. For clarity, the assessment relies on the distinction between social care and health care. Social care is funded by individuals or social services, while health care should be funded by the NHS. Individuals may be awarded NHS funding when they are considered to have an 'overall need' for health care.

9.10. People with dementia are not automatically entitled to NHS continuing healthcare funding. Continuing healthcare funding is given when people meet criteria set by the NHS and undergo an individual assessment.

9.11. Having a primary health need is not about the reason why an individual requires care or support, nor is it based on their diagnosis; it is about the level and type of their overall day-to-day care needs to be taken in their totality.

9.12. The process of assessment and decision-making should be person-centred. This means placing the individual, their perception of their support needs, and their preferred models of support at the heart of the assessment and care-planning process. When deciding on how their needs are met, the individual's wishes and expectations of how and where the care is delivered, and how their personal information is shared, should be documented, and taken into account, along with the risks of different types of provision and fairness of access to resources.

9.13. A capacity assessment would also form part of the assessment process and evidence from family members as well as care staff and other professionals is considered.

9.14. In Jeans case, such an assessment (neither social care or CHC) was never facilitated and thus she self-funded her place in the care home. Without hindsight bias it is not possible to say what the outcome of either assessment would be, but consideration for an assessment may have been helpful for Jean and her family. The family were not aware of this process and would not have known to enquire about that.

9.15. In summary the learning from this episode is that there were missed opportunities to use the Care Act (2014) and the National Framework for NHS Continuing Healthcare (2018) to evaluate Jean's needs prior to and/or during the timeframe of this review.

Key practice episode 2

9.16. The focus of this episode related to the coordination and oversight of care during the timeframe of the review.

9.17. At the beginning of Jean's time in the care home there was a conversation with the family about DNACPR decisions. This was shared by the GP practice with the District Nursing team to confirm that "medical problems should be treated actively including hospital admission if appropriate". The family subsequently provided clarity on LPA decisions which could have prompted a multi-disciplinary team meeting (MDT) to consider the care provided to Jean.

9.18. It was clear to see evidence of good individual practice and attempts to work with other agencies. There are multiple conversations, telephone calls and escalations evident that attempt to coordinate care planning. However, in considering the combined chronologies it does not appear that there was a coherent multi-agency care plan that was understood by family members or reflected Jean's wishes.

9.19. The bigger picture demonstrates inconsistent coordination and a lack of multi-agency planning. Whilst there were occasions where care home staff, clinicians and family talked together, there was not an MDT meeting coordinated. The GP did suggest that one would be useful, however it was not clear where the expectation was in terms of who would organise this.

9.20. It is important to consider the context of the care provision. In particular, the differences between a care home and a nursing home. Both nursing homes and residential care homes provide care and support 24 hours a day, however the main difference is that a care homes provide personal care and support for people who need help with daily tasks, such as washing, dressing or eating, but do not need nursing care. It has been established that Jean was never formally assessed in terms of her needs.

9.21. Therefore, care is not delivered by “Registered Nurses” in a residential care home. The clinical input/ decision making for patients in a care home is provided by a range of other clinicians including, in Jean’s case the GP and District Nursing team. This can also include many other practitioners and services.

9.22. Within this Review the multi-disciplinary care plan refers not only to the plan in place within the care home but also the wider clinical decision-making plan. An MDT refers to a formally arranged and minuted meeting to review all aspects of care both within the home and all the clinical input. An MDT did not take place during Jean’s time within the care home.

9.23. This family describe feeling excluded from decision making and care planning, Jean’s wishes and feelings not being evident and several emerging communication difficulties between the family, GP, and care home.

9.24. Multi-disciplinary planning should have been seen as essential. It would have facilitated the exchange of information, for example with respect to strategies for communication, care planning and to meet Jean’s emotional needs when she was distressed.

9.25. The relationship between family members and agencies became particularly problematic with family feeling that they did not have full oversight of what was happening to Jean. This resulted in the family making phone calls to the GP to try and ascertain details and plans.

9.26. The care home articulate that they were following the clinical advice of the GP and District Nurse. A tangible example may be the Sertraline prescription which was temporarily ceased after family discussed this with the GP as they thought it may be causing nausea. It was subsequently re-commenced without seeking the views of the family.

9.27. Jean’s family reflect that they felt excluded and felt that they were perceived as obstructive when questioning professional views and clinical decisions. However, it should be noted that family members are powerful advocates for their loved one and understand their needs better than anyone, so supporting them through good information and shared goals helps them to advocate effectively for their family member. If there was a barrier to communication this should and could have been addressed by getting all the agencies together to understand how it could be overcome.

9.28. Analysis of this key practice episode acknowledges that there was a barrier in working with Jean's family that impacted on robust planning and coordination. An opportunity to work together to overcome that was not facilitated. The panel agreed that there was sufficient reason for a multi-disciplinary meeting to have been triggered for Jean.

9.29. In summary if an MDT had been coordinated on admission and/or during Jean's time within the care home, the overall multi-disciplinary care plan, understanding of the trajectory of dementia, presentation and communication would have been much improved. Additionally, an opportunity to consider the findings in Key practice Episode 1 could have been facilitated.

Key Practice Episode 3

9.30. In the absence of formal needs assessment, CHC assessment or documented MDT planning, it is difficult to ascertain the extent to which Jean's wishes and feelings are reflected in her overall care.

9.31. It is recognised that the trajectory of dementia is often rapid deterioration that family members are not prepared or ready for, and this naturally leads one to question how families can be best supported with this.

9.32. Dementia is a highly complex and challenging condition. It can present differently from person to person, having a huge impact on the patient, their family, and their carers.

9.33. The NICE Guideline for Dementia reinforces the focus on person-centred support, placing a particular emphasis on involving people with dementia in every decision about the care they receive. The guideline also discusses the various forms of dementia, how it may affect individuals in different ways and how support will therefore be adapted for each person.

9.34. Best practice recommends that everyone diagnosed with dementia should have an individual care plan that is reviewed at least once a year. As Jean's care and support needs were never formally assessed, this was not reflected.

9.35. The panel members reflected that there was a very rapid deterioration for Jean after she moved to the care home, whilst the family had some initial support from the Alzheimer's Society it does not appear that they received any further advice or support to prepare them for this.

9.36. Considering the principle of person-centred care, there is limited evidence that Jean's wishes and feeling influenced her overall care plan and clinical decision making. To reiterate, the care plan referred to within this review is the overall multi-disciplinary plan of care and not solely the plan in the care home. The care in the combined agency information is suggestive of a more functional or medical model delivery of care rather than person centred coordination by all agencies.

9.37. Person-centred care is essential to good dementia care and the underlying philosophy of the Dementia Care Practice Recommendations. It should be noted that this care home is a specialist home for people with Dementia and their CQC inspection demonstrated “good” practice across all the elements.

9.38. The transition for Jean into a home was difficult for her to understand and the family were devastated that they could no longer care for her and keep her safe at home. The view of the family is that staff did not get to know Jean as well as they would have expected, her personality, likes or dislikes because there was often no continuity of care. They do highlight that there were staff who were very kind to Jean, but the staff members were not always consistent which made it difficult for people to get to know her.

9.39. It was recognised by the panel that working shift patterns can sometime pose a challenge in terms of continuity of care provision. The family report their observations that some staff were leaving, and some shifts were short-staffed. This finding is not reflected in the staffing ratio or turnover in the care home at that time.

9.40. It would have been helpful and good practice to have outlined the expectations and contribution of family involvement from the outset and to have kept this under constant review in the context of regular meetings.

9.41. Dementia is a life limiting and degenerative condition and to promote wellbeing various thing may have made a difference such as coordinating meetings, involving the family in a different way and overall, this would enhance the person-centred nature of the care provided.

Key Practice Episode 4

9.42. The Section 42 enquiry concluded that Jean “may have not received an adequate amount of health led input in the prior days to her being admitted to hospital. The care home may have needed to be more insistent with the health services due to not being able to manage her increasing care needs”.

9.43. Although it appears that Jean’s dementia had advanced rapidly during the timeframe of this review, during July and August there were a number of concerning medical symptoms that required coordination.

9.44. The agency reports demonstrate a high level of activity related to those symptoms in the form of phone calls, visits, attention to skin integrity, investigations, and medication reviews- largely this comprised of the District Nursing Team, the GP practice and the care home staff. We have already considered that the lack of MDT discussion and the communication breakdown with the family were factors in why the overall care was not coordinated as coherently as it should have been because all the professionals and the people that knew Jean best were never in the same room to consider all the aspects of care together.

9.45. The information available to this review is suggestive that coordination of care and escalation of concerns may have been expedited in a timelier way.

9.46. The family have explained that it has caused them much distress to reflect on the time immediately before Jean’s death and how they wish they had been more persistent when they knew Jean was unwell and deteriorating. It is evident that they raised on many occasions their concern about Jean, they requested medical review and questioned whether Jean should be in hospital. There was insufficient appreciation that Jean’s son and daughter were desperately concerned about Jean’s deteriorating health.

9.47. Jean herself was telling her Son and Daughter that she did not feel well and asked for help, it is not evident that this was taken seriously enough. Jean expressed (to her family) that the staff were not recognising or acknowledging the fact that she was unwell and were just leaving her to get on with it.

9.48. It is important to note in consideration of the point above that care home staff did continue to communicate regularly with the GP and District Nurses to highlight concerns about deterioration. There is evidence within the chronologies that concerns had been escalated several times to the GP and the District Nursing team. The panel discussion posed the question of what point a decision should be made to “override” a clinical decision, in this case for care home staff to decide to call an ambulance. The panel agreed with the findings of the S42 and felt that this could have been more timely.

9.49. Care staff often find themselves in the position of supporting vulnerable people who are not able to speak up for themselves because of factors such as illness, mental capacity, or social position. Carers, Nurses and Doctors are all part of the same multidisciplinary team and if there is a barrier to communicating with each other or a difference of opinion about a patient, it should be considered and addressed. This may consist of a better model of MDT processes, the “key worker” approach, staff supervision and support. This is considered in Key Practice Episode 3.

9.50. In Jean’s case there was a perceived difference of opinion between the family, the care home, and the GP about her deteriorating health and whether to access emergency/ hospital care. This was subsequently raised in the S42 enquiry and thus careful consideration should be given to escalation processes in this instance.

9.51. In the 2 weeks prior to her death Jean was distressed, she had abdominal pain, frequent diarrhoea, weight loss and skin integrity issues. There were a number of investigations carried out (blood tests, stool samples, urine test) and antibiotics prescribed, this is reflected in multiple telephone calls between professionals, also calls from the family who were trying to understand the plan. The family have also identified that there was a delay in obtaining some of the test samples that had been requested.

9.52. It is helpful to consider what deterioration means and how it is assessed and communicated. The term “deterioration” can be defined as when a patient moves from their normal clinical state to a worse clinical state. This increases their risk of morbidity, organ failure, hospital admission, further disability and even sometimes death.

9.53. It has been established that there were concerns that Jean had deteriorated significantly in the weeks leading up to her death. The S42 findings have been considered with a particular emphasis on the timeliness of Jean being taken to hospital.

9.54. The panel discussion raised some questions about the interface with a care home and local health providers. In Jean’s case the care home consulted with the GP, the District Nursing team and they also accessed the “admission avoidance” team. These are all mechanisms of escalation when there is concern about a patient.

9.55. This promoted consideration about where care homes access support and supervision. There is a non-profit organisation named “West Sussex Partners in Care” which represents adult care providers in the county. However, the support referenced in this review refers to the more operational challenges that care homes may experience and, in these instances, where they can seek advice.

9.56. There are multiple tools, resources and training to manage a deteriorating patient in the care home setting that reflect the “softer signs” of deterioration that care home staff or family members may observe. The care home in this case use the Stop and Watch Early warning tool which is communicated via an SBARD (Situation, Background, Assessment, Recommendation & Decision) method of communication. Essentially there were a number of areas that demonstrated deterioration such as communication changes, concerns about hydration, nutrition, pain, bowel movements, weight changes, mobility and skin integrity that could be observed in Jean’s case.

9.57. To summarise, it is evidenced and established in the chronologies and the conversations with the family and panel members that there was concern that Jean’s health had deteriorated. It was agreed that there were some difficulties in terms of escalation and communication about the level of concern and what weight was given to that.

9.58. In view of the findings of the S42 and the information considered for this review, it appears that the response to Jean's deteriorating health particularly in the week leading to her death could and should have been more timely.

10. Key Findings

Finding 1

10.1. Whilst the timeframe of this review starts when Jean moved into a care home, there was opportunity before and after for formal framework to be used to assess Jean's needs. Namely a needs assessment and a Continuing Healthcare Assessment. Both processes would have aided Jean and her family to be clear on her needs.

10.2. It is recognised that we cannot guess at the outcome that these assessments may have reached.

10.3. This was a missed opportunity for the coordination of Jean's care to have been informed by assessments under statutory and formal frameworks.

Finding 2

10.4. The overall coordination of Jean's care was fragmented with no opportunity for all professionals to meet with the family to ascertain together what that package of care should look like.

10.5. There was a missed opportunity to use the multi-disciplinary model which is an approach that assumes that all professionals' viewpoints and expertise are valuable in the decision-making process. This, together with Jean and the family contribution would have resolved many of the issues in terms of communication and planning.

Finding 3

10.6. During the timeframe of the review there was limited evidence that Jean's wishes and feeling had been considered.

10.7. There was a missed opportunity to develop of person-centred multi-disciplinary care plan for Jean. This relates closely to Finding 2.

Finding 4

10.8. Despite a high level of activity in the time leading up to Jean's death there was a lack of coordinated response to Jean's deteriorating health.

10.9. There was a missed opportunity to utilise an MDT process to ensure a coherent, collective, and timely response. This may have not changed the outcome, but it is likely to have changed her experience and that of the family.

10.10. There is a lack of clarity in the interface and connectivity between the care home and the wider health and social care system.

11. Conclusions

11.1. The move into a care home was a distressing and difficult time for Jean and her family. Leading up to this they received very little advice and support and without any knowledge or experience in Dementia care or how to navigate the health and care system they managed this process entirely themselves. There are statutory and national frameworks that should have been considered and facilitated by one or more of the agencies that knew Jean.

11.2. Prior to and during the time that Jean lived in the care home there was a lack of robust, effective, and coordinated multi-agency work to manage her deteriorating health. There was no occasion in this case that all those who knew Jean were convened to share information and what they had learned about working effectively with her. The family contribution to this should have been essential.

11.3. Both of the above findings would have promoted the principles of person-centred care which should underpin good practice in dementia care. These principles assert:

- The human value of people living with dementia (regardless of age or cognitive impairment) and their families and carers.
- The individuality of people living with dementia and how their personality and life experiences influence their response to dementia.
- The importance of the persons perspective.
- The importance of relationships and interactions with others to the person living with dementia and their potential for promoting wellbeing.
- In addition, the importance of taking account of the need of carers (family, friends, or paid care worker) ad supporting and enhancing their input.

11.4. The available evidence does not demonstrate the extent to which the agencies considered together how Jean’s views, wishes, feeling or personality should influence her care.

11.5. The review found that the interface, connectivity and support systems between the care home and the wider health and social care system could be strengthened.

11.6. Finally, the review supports the conclusion of the section 42 enquiry and concludes that a more timely response to her deteriorating health presentation could have been coordinated to limit ongoing pain and suffering.

12. Recommendations to the Board

Arising from the analysis undertaken in this review it is recommended that the West Sussex Safeguarding Adult Board:

1. Reviews and enhances the understanding of application of needs assessments under The Care Act (2014) to ensure that the workforce offer this to people with dementia and their families/ carers to promote wellbeing, preventative measures, access to information and advice, assessment, eligibility, and capacity assessments.

2. Reviews and enhances the understanding of the National Framework for NHS Continuing Health Care to facilitate assessment of eligibility for patients with Dementia.

3. Reviews the escalation policy to ensure that there is respectful challenge whenever a professional or agency has a concern about the action or, inaction or decisions of another, always keeping in mind that the adult at risk's safety and welfare is paramount.

4. Seeks reassurance from commissioning and provider organisations regarding models of coordination for patients with dementia and if there is sufficient regard to care/family contribution.

5. Seeks reassurance from statutory health and social care agencies that there is adequate support in place to improve the interface between (non-nursing) care homes and the wider systems, this should include a review of the clinical input models that are currently in place.

6. Seeks reassurance from statutory health and social care agencies regarding their interface with the "care home" setting including their access to multi-agency training and wider safeguarding networks.

7. Seeks reassurance that Person-centred care is accurately understood, and that understanding is embedded in practice across partner agencies.

Additionally, although outside of the terms of reference for this review it should be noted that there was a challenge to the initial application of criteria for a Safeguarding Adult Review and therefore WSSAB with its partner agencies should review their shared understanding of the relevant legislation regarding referral and commissioning of SARs to ensure this accurately reflects the absolute and discretionary duties within Section 44, Care Act 2014.

13. References

1) Section 42, The Care Act (2014)
2) Section 44, The Care Act (2014)
3) *The Care Home Inspection report, CQC (2018)
4) National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (2018)
5) LPA, Section 9, Mental Capacity Act (2005)
6) Dementia: assessment, management and support for people living with dementia and their carers, NICE (2018)
7) Dementia Care Practice Recommendations, Alzheimer's Association (2018)
8) Deteriorating Patient, ASHN Network, NHS Improvement (2018)