DACORUM COMMUNITY SAFETY PARTNERSHIP DOMESTIC HOMICIDE REVIEW OVERVIEW REPORT

Report into the death of Sarah
March 2019

Independent Chair and Author: Mark Wolski

Date of Completion: October 2021

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Glossary

Abbreviation / Acronym	Full meaning
AAFDA	Advocacy After Fatal Domestic Abuse
ACS	Adult Care Services
ANC	Admiral Nurse Care
AS	Alzheimer's Society
CCO	Community Care Officer
CinH	Carers in Hertfordshire
CH	Care Home
CHC	Continuing Healthcare
CNS	Community nurse service
CSNAT	Carers Support Needs Assessment Tool
CSP	Community Safety Partnership
DA	Domestic Abuse
DHR	Domestic Homicide Review
DNACPR	Do not attempt cardiopulmonary resuscitation
EMDASS	Early memory Diagnosis and Support Service
GP	General Practitioner
HPFT	Hertfordshire Partnership University NHS Foundation Trust
HoSF	Hospice of St Francis
HSAB	Hertfordshire Safeguarding Adults Board
IMR	Individual Management Review
JSNA	Joint Strategic Needs Assessment
LPA	Legal power of attorney
MDT	Multi-disciplinary team meeting
RAG	Responsible Officers Group
TIA	Transient Ischemic Attack
WHHNT	West Hertfordshire Hospitals NHS Trust

1. INTRODUCTION

1.1 Domestic Homicide Reviews (DHRs) were established under Section 9(3), Domestic Violence, Crime and Victims Act 2004.

1.2 This report of the DHR (hereafter 'the review') examines agency responses and support given to Sarah (not her real name) and her husband, Samuel (not his real name), Dacorum Borough residents prior to Sarah's homicide at home and his suicide in March 2019.

1.3 Following a call to police from Samuel stating that he had shot his wife because she had severe dementia, police attended and found Sarah inside with a gunshot wound to the chest and found Samuel in the garden with a gunshot wound to the head.

1.4 This Domestic Homicide Review was commissioned by Dacorum Community Safety Partnership (CSP) to consider agencies contact/involvement with Sarah and Samuel for the 2 years prior to their deaths. This relevant period was agreed at the first panel meeting as covering a period of single agency involvement for the first year and a second year when multiple agencies were involved with Sarah and Samuel.

1.5 In addition to agency involvement, the review will also examine the past to identify any relevant background or trail of abuse before the homicide, whether support was accessed within the community and whether there were any barriers to accessing support. By taking a holistic approach, the review seeks to identify appropriate solutions to make the future safer.

1.6 The key purpose for undertaking DHRs is to enable lessons to be learned from homicides where a person is killed as a result of domestic violence and abuse. In order for these lessons to be learned as widely and thoroughly as possible, professionals need to be able to understand fully what happened in each homicide, and most importantly, what needs to change to reduce the risk of such tragedies happening in the future.

1.7 This review process does not take the place of the criminal or coroner's courts, nor does it take the form of a disciplinary process.

1.8 The Review Panel expresses its sympathy to the family and friends for their loss and thanks them for their contributions and support for this process.

2. TIMESCALES

2.1 The Dacorum CSP, in accordance with the 'Statutory Guidance for the Conduct of Domestic Homicide Reviews' commissioned this DHR. The Home Office were notified of the decision in writing on the 11th April 2019.

2.2 Mark Wolski was commissioned to provide an Independent Chair (hereafter 'the chair') for this DHR on 24th October 2019. The completed report was passed to the CSP on the 4th April 2022. It was submitted by the CSP to the Home Office Quality Assurance Panel the following week.

2.3 Home Office guidance states that a review should be completed within six months of the initial decision to establish one. The timeframe for this review was considerably extended for several reasons:

- The first panel meeting was not held until 22nd November 2019 to ensure all agencies could attend.
- To enable contact with friends and colleagues

- The coronavirus pandemic resulted in all ongoing DHRs in Hertfordshire being paused.

3. CONFIDENTIALITY

3.1 The findings of this report are confidential until the Overview Report has been approved for publication by the Home Office Quality Assurance Panel. Information is publicly available only to participating officers/professionals and their line managers.

3.2 This review has been suitably anonymised in accordance with the statutory guidance.

3.3 The following pseudonyms have been in used in this review for the victim and perpetrator (and other parties as appropriate) to protect their identities and those of their family members: These pseudonyms were selected following discussion at the panel.

Pseudonym	Relationship	Age at the time of the incident	Ethnicity
Sarah	Victim	82	White British
Samuel	Husband	82	White British
Ann	Daughter	n/a	White British
David	Son	n/a	White British

3.5 As per the statutory guidance, the chair and the Review Panel are named, including their respective roles and the agencies which they represent.

4. TERMS OF REFERENCE

4.1 The full terms of reference are set out at **Appendix A**. This review aims to identify the learning from the homicide, and for action to be taken in response to that learning with a view to preventing homicide and ensuring that individuals and families are better supported.

4.2 The Review Panel comprised of agencies from the Dacorum area, as the victim and perpetrator were living in that area at the time of the homicide. Agencies were contacted as soon as possible after the review was established to inform them of the review, their participation, and the need to secure their records.

Purpose

4.3 The purpose of the review is specific in relation to patterns of domestic abuse and/or coercive control, and will:

- Establish how effective agencies were in identifying Samuel and Sarah's; health and social care needs, care, and support needs and in providing support.
- Establish the appropriateness of single and inter-agency responses to both Samuel and Sarah, during the relevant period.
- Establish whether and to what extent the single and inter-agency responses to any concerns about domestic abuse and/or coercive control were effective.
- To establish how well agencies worked together and to identify how inter-agency practice could be strengthened to improve the identification of, and safeguarding of, vulnerable adults where domestic abuse is a feature.
- Identify, on the basis of the evidence available to the review, the need and required actions to improve policy and procedures in Hertfordshire, and more widely.

- State clearly, where apparent, when the death(s) were deemed to be preventable and the rationale behind this. The CSP and panel were aware that the statutory guidance no longer requires this point but agreed to retain in this case.

4.4 Case Specific Terms - Key Lines of Enquiry

4.4.1 Term 1 - Information:

How was information about Samuel and Sarah health and social care needs received and addressed by each agency and how was this information shared between agencies?

4.4.2 Term 2 - Assessments and diagnosis:

- What was the impact of Sarah's mental health and well-being on Samuel's physical and mental health and well-being?
- Were there any recent changes in Samuel and Sarah physical or mental health and well-being that may have affected Samuel's behaviour?
- Was there any evidence that Sarah's condition had an impact on Samuel's mental health.
- Could the physical or mental health and well-being of Sarah or Samuel have compounded any safeguarding concerns or considerations or masked evidence of domestic abuse and/or coercive control? Did this result in specific or increased risk and missed opportunities for agencies to probe and respond effectively?
- Is there any clear information in relation to domestic abuse and/or coercive control and its impact? Were any carer's/agency assessments completed?
- Were any carer's/agency assessments completed on any family member?
- Was there any indication or sign of any cultural perceptions or beliefs that were relevant? Did these bring with them any implications on the relationship and behaviours?
- Were there any barriers to seeking support? What were they? How can these be overcome?

4.4.3 Term 3 - Contact and support from agencies:

- What was the nature and extent of the contact each agency had with Sarah, Samuel, and family?
- What support did they receive and from whom, individually and as a family?
- Were there any indicators or history of domestic abuse and/or coercive control? If so, were these indicators fully realised and how were they responded to? Was the immediate and wider impact of domestic abuse on Sarah fully considered by agencies involved?
- Was there any collaboration and coordination between any agencies in working with Sarah and Samuel individually and as a family? What was the nature of this collaboration and coordination, and which agencies were involved with whom and how? Did agencies work effectively in any collaboration and did services work effectively with those working with the family?
- Were there any issues of intersectionality identified and how were they dealt with by agencies? Did the interventions of agencies demonstrate competent strategies and practice of intersectionality in their responses?
- What lessons can be learnt in respect of domestic abuse and/or coercive control, how it can affect adults, children, and young people and how agencies should respond to any impact?

5. METHODOLOGY

5.1 The decision to undertake this DHR was taken by the Chair of Dacorum Community Safety Partnership.

5.2 The Review has been conducted in accordance with Statutory Guidance under S9(3) Domestic Violence, Crime and Victims Act (2004) and the expectation of the Multi-Agency Statutory Guidance for the Conduct of Domestic Homicide Reviews December 2016.

5.3 Coronial proceedings were ongoing at the time the review commenced but had concluded by the time the second panel meeting was held. (See 13.6)

5.4 This review has followed the statutory guidance. On notification of the homicide, agencies were asked to check for their involvement with any of the parties concerned and secure their records. The approach adopted was to seek Chronologies initially, followed by Individual Management Reviews (IMRs) for all the organisations and agencies that had contact with Sarah and Samuel

5.5 Independence and Quality of IMRs: The IMRs were written by authors independent of case management or delivery of the service concerned, save for the care home, where it was apparent that senior managers for the care home were acquainted with Sarah and Samuel and their contribution was considered as being of significant benefit to the review. IMRs received were comprehensive and enabled the panel to analyse the contact with Sarah and Samuel.

Documents Reviewed

5.6 In addition to the IMRs, documents reviewed during the review process have included:

- Police summary of key evidence,
- Demographic information from the local Joint Strategic Needs Assessment and a local ward profile
- Local agency policies including;
- Dacorum Borough Council Equal Opportunities Policy;
- Hertfordshire Partnership University NHS Foundation Trust Equalities Policy and Domestic Abuse Policy;
- Safeguarding Policy for Care Home;
- Domestic Abuse Policy Dacorum Borough Council (2019);
- West Hertfordshire Hospital NHS Trust Domestic Abuse Policy;
- Hertfordshire Domestic Abuse JSNA (Draft) 2020;
- Hertfordshire Adult Safeguarding JSNA (2016);
- Hertfordshire Safeguarding Adults Board Multidisciplinary Guidance for Complex Cases 2020

Panel Meetings

5.7 Review Panel meetings took place on 22nd November 2019, 13th February 2020, 13th October 2020, 17th March 2021, 5th August 2021and 23rd September 2021. Whilst progress of the DHR was hindered by the coronavirus lockdown, the chair held several one-to-one discussions with panel representatives to seek clarification on points within agency IMR's between October 20 and February 21.

6. INVOLVEMENT OF FAMILY, FRIENDS, WORK COLLEAGUES, NEIGHBOURS AND WIDER COMMUNITY

6.1 Sarah and Samuel had two surviving children, one of who had taken on the lead responsibility for dealing with the authorities and Homicide Support Service.

6.2 At the start of the review, coronial proceedings were ongoing, and the family were still in contact with the police via the family liaison officer and were in receipt of support from the Homicide Support Service. The chair subsequently informed them of support available by Advocacy After Fatal Domestic Abuse (AAFDA).

Sarah and Samuel Children

6.3 The chair has sought the views of Sarah and Samuel's children, Ann, and David, through the Homicide Support Service and Family Liaison Officer. It was made clear at the first panel meeting through the police family liaison officers that neither of the children wanted to take part in the DHR process. The chair wrote to Ann in November 2019 outlining the purpose of the DHR process, the support available and referenced the family DHR leaflet. This was delivered by the Homicide Support Service and in response, their daughter kindly wrote to the chair and panel. Similarly, their son was contacted through the family liaison officer and initially declined to take part in the review process.

6.4 In April 2020, as the coronavirus lockdown became established, the chair spoke to the family liaison officer and asked about further family contact. Whilst Ann had asked not to be involved, the chair asked the liaison officer to speak to David and ask whether he would be willing to speak on the phone to the chair.

6.5 In the first week of May, the chair spoke to David and explained the DHR process. He followed this up, providing him with links to the Home Office information, DHR leaflets and sent the terms of reference for the review. The chair explained the services of Victim Support for Homicide and AAFDA.

6.6 On the 20th May, a video-conference call took place, and the chair explained the process in greater detail, outlined the terms of reference and secured some background detail as outlined at 14.1.9. It was agreed that further contact be made, after David had time to digest the process and the terms of reference that were sent to him after the meeting.

6.7 The chair sent further emails in June, attempting to organise a further meeting in advance of the chairs meeting with the GP. This was not possible as David was busy. As the review progressed, further attempts were made to have more detailed conversations, with contact being made in September and October 2020, and again in July, August, September, and October 2021.

6.8 The chair was able to meet with David via a video conferencing in February 2022, when he gave an overview of the process and went through the findings of the review. The pseudonyms were agreed at this meeting.

Friends and Family Statements

6.9 The police provided the chair with a case summary that included a precis of statements from five friends. The chair also reached out to friends of Sarah and Samuel through the police initially and then through the wider network of community contacts made available through panel representatives. There was a limited response, but the chair was able to speak in person

to one close friend (January 2020) and two further friends (February and March 2020) who had also known them for a number of years.

7. CONTRIBUTORS TO THE REVIEW

7.1 The following agencies were requested to complete Individual Management Reviews and Chronologies and documents received are noted as below.

Organisation	Documents Received/Reviewed
GP Practice	Chronology
West Hertfordshire Hospital NHS Trust	IMR and chronology
Adult Care Services	IMR and chronology
Carers in Hertfordshire	IMR and chronology
Hertfordshire Partnership University NHS Foundation Trust	IMR and chronology
Hertfordshire Community NHS Trust	IMR and chronology
Hertswise (AgeUK)	Chronology
Crossroads Care Hertfordshire	IMR and chronology
Alzheimer's Society	Chronology
Hospice of St Francis	Chronology and Case Reflection Notes
Care Home	IMR and chronology

7.2 Individual 'virtual' meetings took place between the chair and agencies who had not submitted IMR's as follows.

Organisation	Representative
GP Practice	Practice GP
Hertswise (AgeUK)	Mark Hannah, Operations Director
Alzheimer's Society	Steve Hampson
Care Home	Diane Delicate

8. THE REVIEW PANEL MEMBERS

8.1 The Review Panel included the following agency representatives.

Name	Title	Agency
Sue Warren	Safeguarding Lead Officer	Dacorum Borough Council
Mark Wolski	Independent Chair and Author	Independent Chair
Dawn Bailey	Named Nurse for Adult Safeguarding	West Hertfordshire Hospitals NHS Trust
Naomi Bignell	Named Nurse Safeguarding Adults	HCT
Danielle Davis	Senior Development Manager DA	Herts County Council
Diane Delicate	Manager	Care Home
Michael Farrell	Chief Executive	Crossroads Care
Deirdre Haynes	Deputy Head of Services	Adult Care Services, HCC

Name	Title	Agency
Kelly Huxstable	Deputy Manager	Care Home
Clare Landy	Specialist Safeguarding Practitioner	Hertfordshire Partnership Foundation Trust
Victoria Lyons	Senior Consultant	Dementia UK
Aimee Martindale	Services Manager	Crossroads Care
Steve O'Keeffe	Detective Chief Inspector	Hertfordshire Constabulary
Graeme Walsingham	Detective Chief Inspector	Hertfordshire Constabulary
Fay Richardson	Director of Care,	Hospice of St Francis
Carole Whittle	Health & Wellbeing Manager,	Carers in Herts
Tracey Cooper	Associate Director Adult Safeguarding	E&N Herts and Herts Valleys Clinical Commissioning Group
Martina Palmer	Senior Operations Manager	Refuge
Claire Stockwell-Lance	Area Manager	Alzheimer's Society
Katherine Johnson	Consultant Social Worker	Herts Partnership NHS Foundation Trust

8.2 Agency representatives were of appropriate level of expertise and were independent of the case.

9. AUTHOR OF THE OVERVIEW REPORT

9.1 The Chair of the Review was Mark Wolski. Mark has completed his Home Office approved Training, subsequent Training by Advocacy After Fatal Domestic Abuse and the foundation course for the social care institute for excellence 'Learning Together systems model for case reviews'. He completed 30 years exemplary service with the Metropolitan Police Service retiring at the rank of Superintendent. During his service he gained significant experience leading the response to domestic abuse, public protection and safeguarding. (See Appendix B for Statement of Independence).

10. PARALLEL REVIEWS

10.1 Coronial proceedings were ongoing at the start of the review, but concluded on the 9th January 2020 (see 13.6). The coroner was made aware of the Domestic Homicide Review.

11. EQUALITY AND DIVERSITY

11.1 The nine protected characteristics as defined by the Equality Act 2010 have all been considered; they are age, disability, sex, sexual orientation, gender reassignment, marriage and civil partnerships, pregnancy and maternity, race, religion or belief and sexual orientation.

11.2 There were a number of protected characteristics requiring consideration. The first was the sex of Sarah. She was female, and Samuel was male. An analysis of DHRs reveals gendered

victimisation across both intimate partner and familial homicides with females representing the majority of victims and males representing the majority of perpetrators. [1]

11.3 One of the protected characteristics also considered to have relevance to this DHR was Sarah's disability through dementia that had a 'substantial' negative effect on her ability to do normal day to day activities.[2]

11.4 On considering her Dementia and the Equalities Act, it is incumbent on this review to consider the duty on public authorities to;

- remove or reduce disadvantages suffered by people because of a protected characteristic.
- meet the needs of people with protected characteristics.
- encourage people with protected characteristics to participate in public life and other activities[3]

11.5 The third protected characteristic requiring consideration, is that of age. There have been a number of reports describing the systematic invisibility of the elderly in relation to Domestic Abuse. [4] The chair also notes that the British Crime Survey in relation to Domestic abuse had until 2017 only included those aged 16 to 59, but now includes those aged 60 to 74.

11.6 These issues are discussed further at 16.15 below.

12. DISSEMINATION

12.1 Once finalised by the Review Panel, the Executive Summary and Overview Report will be presented to the Hertfordshire Safeguarding Adults Quality and Innovation sub-group and the Dacorum Community Safety Partnership (CSP) Responsible Authorities Officers Group (RAG) chair of the Executive for approval and thereafter will be sent to the Home Office for quality assurance.

12.2 Once agreed by the Home Office, the CSP in conjunction with the Hertfordshire County Council, Domestic Abuse Strategic Partnership team will ensure the learning is shared.

12.3 The Executive Summary and Overview Report will also be shared with the Police and Crime Commissioner for Hertfordshire, the agencies listed as contributing to the review, those shown at appendix C, and will also be published on the council's website.

12.4 The action plan will be monitored by the CSP.

13. BACKGROUND INFORMATION (THE FACTS)

13.1 Family Make Up

[1] Source: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/575232/HO-Domestic-Homicide-Review-Analysis-161206.pdf (Accessed December 2019)

[2] Source: https://www.gov.uk/definition-of-disability-under-equality-act-2010 (Accessed December 2019)

[3] Source: https://www.citizensadvice.org.uk/law-and-courts/discrimination/public-sector-equality-duty/what-s-the-public-sector-equality-duty/ (Accessed December 2019)

[4] Source: https://safelives.org.uk/sites/default/files/resources/Safe%20Later%20Lives%20-%20Older%20people%20and%20domestic%20abuse.pdf (Accessed December 2019)

13.1.1 Sarah and Samuel had been together for more than 60 years and celebrated their golden wedding anniversary in 2016. They have left two adult children, one of whom had emigrated.

13.1.2 They lived in the same family home, that Sarah's father had built for the duration of their marriage.

13.2 Summary of Events Leading up to the Homicide

13.2.1 In February 2018 Sarah was diagnosed with subcortical vascular dementia, and her health steadily deteriorated. She was unable to recognise close members of her family or recall recent events.

13.2.2 Samuel had his own health issues, being diagnosed with cancer and diabetes. He tried to care for Sarah at home with the assistance from family and a variety of agencies. As her condition worsened, he found it increasingly difficult, and a decision was made that she would have to go into a care home for people with dementia. She was due to move into the care home in late March 2019.

13.3 The Events of the Homicide

13.3.1 In March 2019, Hertfordshire Police received a call from Samuel. He stated that he had shot his wife, because she had severe dementia, and that the police would find him out in his back garden as he was going out there to shoot himself next. Samuel then attempted to ask the call operator to pass a message to his son David, but as the operator attempted to keep him on the line, he disconnected the call, and the line went silent.

13.3.2 Repeated calls were made to the landline of Sarah and Samuel, but they were unanswered. Police information confirmed that Samuel was a long-term shotgun licence holder, and that he kept his guns in the house, secured by a gun clamp.

13.3.3 At 07:57hrs Hertfordshire Police contacted the Ambulance Service and asked for them to dispatch an Ambulance to the home address, and dispatched firearms officers. At 08:22hrs officers entered the address to carry out a search of the address and locate Sarah and Samuel.

13.3.4 Inside the house, officers found Sarah in a bedroom. She showed no signs of life and clearly had a gunshot wound to the chest.

13.3.5 Police found Samuel in the garden. He showed no signs of life and had a gunshot wound to the head.

13.3.6 There were two notes left in the kitchen, one addressed to the police giving contact details for their children and the other explaining what to do after they have gone.

13.4 Post-Mortem

13.4.1 A post-mortem of Sarah subsequently took place. The cause of death was determined as gunshot wound to chest. There was no evidence of other injuries or assault.

13.4.2 A post-mortem of Samuel subsequently took place. The cause of death was determined as gunshot wound to the head.

13.5 Investigation and Outcome

13.5.1 The Bedfordshire, Cambridgeshire and Hertfordshire Major Crime Unit conducted a comprehensive investigation into the circumstances of their deaths that included interviewing and taking statements from friends and family. As there was no evidence of third-party involvement, the matter was passed to the coroner.

13.6 Coronial Process

13.6.1 The coronial process concluded on the 9th January 2020, where it was concluded that Sarah's death as unlawful killing and that Samuel's was one of suicide.

14. CHRONOLOGY

14.1 Background History – A Family and Friends Perspective

14.1.1 Sarah was one of three children. Her brother had passed away and she had lost contact with her sister many years ago.

14.1.2 Sarah and Samuel had known each other since school and had been together for more than 60 years, celebrating their golden wedding anniversary in 2016. They had two children, Ann, and David. The chair learned from friends that they brought up their family, in the house that Sarah had grown up in herself and that this house had been built by her father.

14.1.3 She had an active life in public service and Samuel having spent a short time in the Army became an engineer.

14.1.4 All their friends describe a loving relationship and that they were absolutely devoted to each other. These friends became aware that Sarah was unwell about three years before the incident and described how Samuel became very protective of Sarah, looking after her needs more as her ability to communicate and look after herself diminished. They were aware of Samuel taking on all the household tasks, from household cleaning, cooking and ultimately looking after Sarah's personal needs to wash and dress. It became apparent to many that Samuel began to struggle as Sarah's condition deteriorated, particularly over the last six months of her life.

14.1.5 In early 2018 Sarah was diagnosed with Subcortical Vascular Dementia, and her health steadily deteriorated since then. She was unable to recognise close members of her family or recall recent events. Despite Samuel's own health issues, he tried his best to care for Sarah at home. As time went by and her condition worsened, he found it increasingly difficult to care for her and a decision was made that she would have to go into a care home for people with dementia.

14.1.6 During their lives, and up to present day it appears that they had an extremely close, loving, and supportive relationship.

Friends Perspective

14.1.7 The chair was able to interview three friends of Sarah and Samuels whose views are summarised in the general overview at 15.1. It seems appropriate to include details of that particular interview to provide a perspective on the relationship of Sarah and Samuel. The notes below reflect the contemporaneous nature of the conversation and have been subject

to minimal alteration, to ensure the authenticity and meaning of a close friend of Sarah and Samuel.

She described them having a charmed and wonderful life. She explained that Sarah and Samuel had been childhood sweethearts, being together since the age of 14 before marrying aged 20. They were very close and couldn't bear to be apart.

Sarah had been a secretary by trade and Samuel had been an engineer. She was quite a character, warm and loving. She was equally formidable, having a strength of character that ensured she enjoyed a successful public life.

She had multiple interests including golf and horse riding, having given riding lessons to many children over the years.

He was a proud man, hugely independent and did not like anyone doing things for him. He found it difficult to accept any help and he would only leave Sarah with this close friend. There had been attempts at carers and on one occasion when they had tried a particular carer, she didn't turn up and he just gave up on the idea. Samuel was like that, impatient, he didn't hang around. She did persuade him to try a carer, that she had used, but then when the carer came, he would stay with them not trusting the carer to care for Sarah. The friend also described he was the same when leaving Sarah with her. He would rush to do his business at the bank or whatever and then rush back.

On asking about the onset of dementia, she recalls that early on they thought Sarah may have been suffering from hearing issues until she had an episode (petit mals) resulting in Sarah being taken by ambulance to the hospital. She reflected that Sarah's refusal to stay in hospital was indicative of her aversion to hospitals and help. They just did not like hospitals or busy places such as London

On describing the effect on Sarah and Samuel and how they lived, she said that towards the end, she had been very worried about Samuel. Sarah would sometimes fall over in the night and therefore he just could not get to sleep. He just wanted to be there for her if she wanted anything and couldn't bear to think if she had an episode and he was not there to help her. As a result, he got very little sleep and found it difficult to cope. He also had his own medical issues and could have had an operation, but just didn't. He was devoted to her.

She says that he was so reliant on his children, and his daughter who had immigrated to Australia, and was trying to work things out, put support in place for them both.

On exploring Sarah's level of understanding and capacity, she made a couple of points. She described that on the one hand she did suffer from some speech impediment, but her friend could understand her. She said, they still used to sit around her house listen to opera and reminisce. There were memory lapses, such as when she used to say to her about the strange man in the other room. Saying 'I rather like the man in the lounge, I'd like to marry him.' The other point was that, that she knew her own mind. Sarah was absolutely adamant that she did not want to leave her home. She wanted to stay there and did not want to move to the care home. She had in the past actually talked about being buried in the back garden or her field that she would walk around.

The chair enquired as to how the agencies, their GP and others had worked with the family. She was very praising of everyone and thought that everyone had tried their hardest to help. She did not think that anything more could have been done. She re-iterated that private help had been available, but that she as a friend could not persuade them to accept help. She thinks that Samuel had had a carers assessment, but the issue was with Samuel that he would not accept help. Either proud, private or both.

An overarching impression for her, was that they just could not be parted, and it was best they went together.

Daughter's Perspective

14.1.8 Whilst Ann did not wish to be involved in the review, she kindly wrote a letter for the attention of the review panel, the contents of which are shown below.

It is imperative that the "investigators" know that what my dad did was an act of total selfless love and devotion for mum to end her suffering from dementia, and he loved her so much he couldn't live without her, so he took his own life. There's was a lifetime love story. I have boxes of cards and poems they have written to each other. They met on a winter sledge field aged 14 and were inseparable until the day they died.

Mum's dementia was at a stage where sometimes she knew us and sometimes, she didn't. The one thing she did know and would say over and over was that she was never leaving her home. Dad knew it would be the ultimate betrayal to mum to place her in a home, but we were at the stage where we couldn't manage mum at home anymore - even if we had had a live-in carer, we knew we needed a team of people and a safer environment. Dad and I coped between us, around the clock, for the last 3 months of their lives but we were struggling and couldn't have maintained it for much longer as mum continued to deteriorate. We arranged Carers to come but they all failed, some never even started.

Dementia, by its nature, affects primarily older people and their loved ones. Help needs to be pitched at those older people - telling them to go online to access things doesn't help when they are over 80 and don't know how to use a mobile phone let alone a computer. They need human help.

Son's Perspective

14.1.9 The chair managed to speak to Sarah and Samuel's son David on a couple of occasions around May 2020. He was appraised of the DHR process, provided with the information of where to seek support in respect of the DHR process and a copy of the terms of reference. However, only one substantive conversation took place prior to a final draft being presented. During this conversation, he provided a brief overview of his parent's relationship and the circumstances leading up to the loss of his parents. He also emailed the chair a short, written summary of his perspective of his father and the overall situation.

"*Dad was born in rented rooms, started work part time at 12, up very early to do papers then on to a milk round then school, Saturdays in a bicycle shop. full time in a factory at 14, dad did 7 years of night school at Watford 18 miles each way twice a week on a bicycle in all weathers, this extreme effort was interrupted by two years national service in Scotland. He kept pushing on until he was as the managing director of the multi-national company said, "the most competent engineer in the company" age 62 he retired, 50 years of taxation led to nothing from the government when he needed help, what sort of a deal is that?"*

14.1.10 In describing his parent's relationship, in which he described Sarah as the dominant character, with Samuel ceding to her. As her illness deteriorated it became difficult for his father, who David thought ought to have taken a firmer hand. He gave an example of where Sarah would slap Samuel when he was trying to help her eat.

14.1.11 On describing the support from agencies, he used the term being passed from 'pillar to post', in expressing frustration with the system that was supposed to support them. It is fair to say that he reflected on a system that his parents and mother had invested their own time and effort to support, championing and supporting the local hospice.

14.1.12 He recalls that the family did ask for support from the local hospice that his mother had supported, but notwithstanding an assessment at home, where Sarah refused to talk, they were unable to assist with respite beds, but provided other support.

14.1.13 When the chair met with David in February 2022, he felt that it was important to reflect on his father with whom it was clear he also enjoyed a close relationship with. He described his father as someone with whom he shared a number of hobbies. His father having taken up golf in 1975, introduced his son as a junior 2 years later. They would enjoy golf and other hobbies such as cycling and a passion for aircraft and flight.

14.1.14 He explained that his father also had a good circle of friends, with men with whom he had completed his national service, and that these friends lasted a lifetime, as he was 'utterly loyal' in all things. He also shared a letter from friends of his parents, an extract of which illuminates their relationship and reflects on how they needed help.

"I had not seen them for ages when I invited them around for a cup of tea here last Autumn and was moved to see how frail Sarah had become, and how lovingly Samuel was attending to her every need. In hindsight, I wish I had realized then, that this couple, who spent their time helping others, could perhaps have done with a bit of help themselves, and I wish I had been more aware of their needs."

14.1.15 The first part of this paragraph, regarding Samuel's care for Sarah becomes apparent throughout this review. The second part about having needed more help, remains true from David's perspective.

14.2 Narrative Chronology

14.2.1 Both Sarah and Samuel had a significant volume of contacts with medical professionals in the last two years of their lives. It is considered important to outline some of the detail within the chronology to show the volume of contact, but also demonstrate how these medical conditions effected their lives. The paragraphs within the narrative chronology are pre-faced with the lead agency to identify the primary source of information and assist the reader.

2017

14.2.2 In 2017, the agency contacts with Samuel and Sarah are limited to contacts with their GP practice, with other entries related to health issues consistent with their age.

14.2.3 ***GP Practice:*** Sarah attended her GP practice on thirty-six occasions during the year, many of which related to physical conditions unrelated to her cognition, others related to her subsequent diagnosis of dementia. There are twenty-eight entries related to Samuel. These varied from routine and unremarkable visits such as flu vaccinations and blood tests.

14.2.4 ***GP Practice****:* Through April to June, there were early references to Sarah's cognition and a note to consider referring to early dementia services. In May a conversation took place between the GP, Sarah, and Samuel about attending the memory clinic. During this period Sarah also attended the GP with Samuel regarding some unrelated matters.

14.2.5 ***GP Practice****:* On the 22nd June, an administrative entry is made, noting an application for a firearms certificate.

14.2.6 In July, Samuel had more frequent contact with the surgery than Sarah. These visits may be considered routine in nature for a gentleman of his age. He also attended West Hertfordshire Hospitals NHS Trust for a review at the Oncology department concluding that a further review

would be needed in six months. There are a number of administrative entries on Sarah's records and a telephone consultation. These appear unremarkable and routine in nature.

14.2.7 ***GP Practice:*** On the 14th July, Samuel presented with a minor head injury. It is noted that he went to A and E and that he had not lost consciousness. He returned to his GP on the 20th and following examination was advised to return in two weeks if he did not feel better.

14.2.8 ***GP Practice****:* On the 6th December Sarah attended the surgery with Samuel in order to review Sarah's condition. It was noted that her memory was problematic, but that she was managing to remain active and sociable. The notes stated that she was 'chatting' appropriately.

14.2.9 ***West Hertfordshire Hospital NHS Trust:*** On 27th December, Sarah had a fall at home and was taken by ambulance to hospital. In attendance at the hospital were Samuel and their daughter Ann and they described 4 similar episodes of collapse in the last 12-18months to the therapist. During the overnight admission Sarah was reviewed by a physiotherapist and the therapist noted that the family are keen to have support. Ann also informed staff that her father was providing a lot of help and is nearing the point of carer breakdown. It was recognised on attendance at the hospital that a social care input was required, that Samuel was at risk of carers' burden and an alert was submitted to adult care services that indicated Samuel required an assessment for a package of care.

14.2.10 During this attendance A Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) decision was made during this visit. It is documented that this was discussed with Sarah and family. It was noted that Sarah lacked mental capacity to consent to the DNACPR. Sarah was discharged the following day and it was noted that when the medical team spoke to the family, Ann emphasised that her father was not coping well. The team reassured her that a referral had been made to social care.

14.2.11 ***GP Practice***: On the 29th December, there is an administrative note regarding Sarah granting permission to discuss medical matters with Samuel and their children.

14.2.12 ***GP Practice:*** On the same day, Sarah was seen by the GP in the presence Samuel and Ann. It was documented that she had been admitted to hospital on the 27th December following a fall. They were informed that Sarah was likely to have vascular dementia and they said they were very keen on support.

2018

January

14.2.13 In 2018, the number of agencies engaged with Sarah and Samuel increased significantly and particularly in respect of Sarah's diagnosis of dementia and offering support to deal with the effects of dementia. Samuel also had variety of consultations owing to his own medical issues such as a referral to cardiology and oncology. Neither required further treatment.

14.2.14 ***West Hertfordshire Hospital NHS Trust****:* On the 4th January, Sarah was seen at a clinic as she may have difficulty maintaining sanitary cleanliness independently with a plan to refer to a specialist nurse.

14.2.15 ***Adult Care Services ACS:*** On the 5th January, ACS spoke to Sarah's daughter Ann who was abroad and agreed an 'Assessment for Access' that is an assessment in respect of stair rails and equipment to facilitate entry to the home.

14.2.16 ***Carers in Hertfordshire***: On the 8th January 'Carers in Hertfordshire' emailed Samuel to acknowledge receipt of his application for a 'Carers in Hertfordshire passport discount card'.

They requested further details about himself, his caring and Sarah. This 'passport' provides financial support through the savings, services and business offers such as discounts/concessions through a variety of outlets.[5] Two days later a further referral was received from Samuel and Sarah's GP. No further action was taken regarding this as initial contact had been made directly with Samuel. The registration process for the passport was subsequently completed on the phone in early February.

14.2.17 ***Hertfordshire Partnership University NHS Foundation Trust (HPFT):*** On the 8th January HPFT received a referral from Sarah's GP. The referral outlined that Sarah had been suffering from increased confusion and that Samuel would require increasing levels of support. Early memory Diagnosis and Support Service (EMDASS) spoke to Samuel on the phone a week later and confirmed arrangements for Sarah to attend a clinic in February.

14.2.18 ***Hertswise (Age UK Herts)***: On the 10th January, Hertswise received their first contact from Sarah's daughter Ann, who explained that Sarah had been diagnosed with dementia for over a year. She outlined that her father Samuel may be unwelcoming of outside help but would be happy to receive advice on power of attorney and Attendance Allowance. Ann subsequently phoned them again and requested that contact was delayed until after the 6th February as Sarah was due to have a care need assessment.

14.2.19 ***Hertfordshire Community NHS Trust:*** Sarah had been referred to the Trust owing to a number of falls. There are number of entries in January that include, on the 12th January an initial Home Visit and assessment by an occupational therapist. Whilst Sarah felt she coped well; her daughter and Samuel felt some equipment would be useful. It was noted that Samuel undertook the domestic chores and was managing well. A selection of practical equipment was ordered included stair rails, bed levers and it was agreed that covers for kitchen units would be explored as Samuel kept banging his head.

14.2.20 ***ACS***: Further contact was made on the 12th and 15th January following a referral by Community Adult Health Services Community Nurse requesting rails to support her with accessing her property more safely. During the first call Samuel relayed to ACS that his granddaughter would benefit from the rails, however, when he called back, he explained that he could not speak openly because his wife was standing next to him and mentioned his granddaughter so that she would not be suspicious. Sarah had just been diagnosed with vascular dementia which her husband said she had not taken well, and he declined the assessment on his wife's behalf stating that she was feeling overwhelmed by the number of assessments already undertaken by other professionals. Samuel informed ACS that he will contact a private contractor to fit the rails and the referral was closed. No conversation took place with Sarah.

14.2.21 On the 18th January West Hertfordshire Hospital NHS Trust received a letter from GP to its Cardiology department. It states that Samuel had been feeling unwell, lightheaded, and experiencing headaches. This has been occurring weekly and that it started some time ago however is now persistent and lasting up to 30 minutes.

February

14.2.22 ***Hertfordshire Partnership University NHS Foundation Trust (HPFT):*** On 5th February Sarah and John attended EMDASS for a diagnostic assessment. The assessment was carried out by the memory nurse and an older age consultant psychiatrist without Samuel being present. They concluded that there had been a decline in Sarah's memory and level of functioning over the previous 12 months. As part of the assessment of need, it was noted that Samuel had taken on the cooking in the household and all the financial management. Sarah

[5] Source: https://www.carersinherts.org.uk/how-we-can-help/carer-services/carers-discount-passport (Accessed March 2020)

agreed that her details could be passed on to the Alzheimer's society for further support and EMDASS then wrote to Sarah's GP recording a diagnosis of Subcortical Vascular Dementia and passed on details to the Alzheimer's Society. A memory nurse was allocated as Sarah's Care co-ordinator from the 5th February to 4th June 2018. However, no contact was made until June as she was deemed as low priority and owing to a waiting list.

14.2.23 ***GP Practice:*** On the same day, Ann contacted Sarah's GP and advised that her father was struggling to cope and needed respite. The GP in turn contacted ACS and it was also noted that the Hospice of St Francis was unable to help.

14.2.24 ***ACS:*** On 6th February, a community care officer (CCO) phoned and spoke to Samuel regarding an access assessment for stair rails and assisting with mobility around the home. He was unable to have a proper conversation initially, as Sarah was standing next to him. During a later call, he explained that Sarah had been diagnosed with vascular dementia and had not taken the news well. A home visit was declined at the time, as being too much for his wife at that time. In the conversation, Samuel confirmed that he had a private contractor he would use for equipment and a closure letter was sent.

14.2.25 ***Hertswise (Age UK Herts):*** Hertswise contacted Samuel in accordance with Ann's wishes on the 7th February. Samuel declined support and Hertswise emailed Ann and tried to call David to let them know. There was no further contact until June.

14.2.26 ***GP Practice:*** During February, Samuel was also suffering from worsening problems with indigestion that was managed through medication pending a referral to West Hertfordshire Hospitals NHS Trust.

March

14.2.27 ***GP Practice:*** In March, there was no direct contact with Sarah by agencies. Samuel contacted his GP on receipt of a specialist medical appointment and asked whether this could be brought forward. His GP subsequently requested this appointment was fast-tracked marking the referral as urgent owing to suspect cancer. This was undertaken on 1st March and followed up in May.

14.2.28 ***Carers in Hertfordshire:*** On 7th March, Carers in Hertfordshire made a follow up call to Samuel to check how he was coping and whether he would like to access any services from Carers in Hertfordshire. He declined any services.

April

14.2.29 ***GP Practice:*** In April Sarah's GP conducted a home visit on the 4th April and two telephone consultations on the 5th and 13th April. During these consultations, Sarah was described as having been lightheaded and having fainted during the night.

May

14.2.30 ***West Hertfordshire Hospital NHS Trust:*** On the 25th May Samuel attended a gastric clinic outpatient appointment at WHHNT. During the consultation Samuel explained that he was the carer for his wife and said that his mood was low, and he was 'a bit under stress'. The GP was informed of this concern by letter after the outpatient appointment.

14.2.31 On the 29th May, Sarah went to her GP with Samuel regarding dizziness, feelings of nausea and not wanting to eat. She was prescribed some medication.

June

14.2.32 ***EMDASS/Alzheimer's Society:*** On the 5th June, Samuel had a telephone consultation with an Alzheimer's support worker. A prepared screening tool was used, and Samuel was referred to the Alzheimer's Society fact sheet online. Samuel consented for his details to be shared with ACS for a carers assessment. In the same call he accepted a referral to EDMASS occupational therapists to assist with the management of risks at home. He consented to a referral to Hertswise to provide information and support an application for Attendance Allowance. He declined an offer for Sarah to attend the next available cognitive stimulation therapy group.

14.2.33 ***EMDASS*** as part of their routine enquiry ask whether there are firearms in the home and it was recorded as "No firearms/weapons advised in the home".

14.2.34 ***ACS:*** On receipt of the information from EMDASS, Samuel was allocated to a CCO in the Dacorum Team for Older People who called him to make an appointment to carry out a Carer's Assessment under the Care Act. The referral described Samuel as struggling in his caring role and feeling tired and exhausted at times. Samuel painted a very different picture of the situation and told the CCO that he was managing, he declined the assessment stating that he only wanted to establish a contingency plan for his wife should he no longer be able to care for her due to his own health issues that were currently under investigation. His family later confirmed that Samuel had been diagnosed with other medical conditions that were being treated and monitored.

14.2.36 ***GP Practice:*** On 12th June 2018, both Sarah and Samuel had consultations. The consultation with Sarah appeared routine in nature. In Samuel's consultation, it was noted that he gets low on occasion, but not depressed.

14.2.37 ***Hertswise (Age UK Herts)***: On the 16th June, Hertswise contacted Samuel again, following a referral from EDMASS and the GP, asking for assistance with Attendance Allowance. He explained that he didn't want to go into eligibility criteria in detail as Sarah gets very upset when talking about her dementia. A further conversation took place on the 29th June and information was provided on the different thresholds for financial assessment. A visit was booked for the 9th July.

14.2.38 ***GP Practice:*** On the 22nd June, Samuel attended the GP to speak about Sarah. He explained that Sarah had collapsed, and the GP agreed to visit later that day. The GP conducted the home visit, the notes showed that Samuel and their daughter Ann were present. During the consultation, it was reported that Sarah had episodes of collapse for 18 months and this latest episode had taken place at 5am. The summary notes record that a referral to the Transient Ischemic Attack (minor stroke) clinic was to be made, the Holistic Care Team were to support Sarah at home and a referral in relation to the 'Care of the Elderly Team'.

July

14.2.39 ***ACS:*** On the 10th July, a home visit was conducted by ACS and Samuel said that he is doing well with his caring role and did not want a carers assessment. He was most concerned about who would look after Sarah if she became unwell. It was confirmed at this meeting Sarah would be required to self-fund as they had sufficient savings. It seemed to the professional that Samuel was reluctant to accept any suggestions for support as Sarah wouldn't like it. A carers contingency plan was completed by a CCO that summarised the support Samuel provided to Sarah and that if her were unable to take care of Sarah, then David should be contacted.

14.2.40 ***West Hertfordshire Hospital NHS Trust****:* On the 11th July, West Hertfordshire Hospital NHS trust (WHHNT) received a referral from the GP explaining that Sarah is having three falls a

week, requesting support and advice around managing the case. Sarah subsequently saw an elderly care consultant on the 16th July. It was reported that Sarah only has fainting issues at night-time when she needs to mobilise. It was reported these problems had been occurring for about a year. Medical advice was given, and medication amended to combat the night-time light headiness.

14.2.41 ***Hertswise (Age UK Herts)***: On the 11th July, Hertswise visited Sarah and Samuel. They noted that Sarah was a good candidate for higher rate attendance allowance. They didn't want to discuss means tested benefits. They noted that attendance allowance (AA) mandatory reconsideration was available if necessary.

14.2.42 ***Hertswise (Age UK Herts)***: On the 18th July, a Hertswise care support worker spoke with Ann and noted details of what had been done already. Ann had said she was really happy with the support and help she has been getting from different organisations. A request was made internally for a member of staff to contact Samuel and Sarah. This was followed up on the 26th and it was understood Sarah would be attending Cogs.[6]

14.2.43 ***GP Practice:*** On the 20th July, Ann had a consultation with the GP. She explained that Samuel was not coping well, and it was noted Ann was leaving in a few days' time. It was suggested that a referral to Hospice of St Francis was required. This referral was received by HoSF a week later on the 27th who advised that Sarah was not at the end of life and that Sarah ought to be referred to Adult Care Services (ACS). This was followed up again on the 30th when the GP spoke to HosF who explained that they had urgent patients requiring available bedspace. Sarah's GP then phoned Adult Care Services and left a message for Sarah's case worker. ACS were unable to determine what happened with this message.

14.2.44 ***ACS:*** On the 30th July the GP phoned ACS and advised them that Ann had contacted the surgery to advise that her father is struggling with his caring role and needs respite. Hospice of St Francis is unable to support.

August

14.2.45 ***Hospice of St Francis:*** On the 7th August HoSF carried out an assessment of Sarah in the presence of her husband. It was noted that Sarah was able to contribute to the conversation and following the consultation, arrangements were made for HoSF physiotherapist to see Samuel and HoSF fed back their findings to the GP. Samuel was provided information on carers assessments and said he would consider it.

14.2.46 ***Carers in Hertfordshire:*** On the 14th August, Samuel spoke to Carers in Hertfordshire to replace his passport card. During the conversation, Samuel explained that both he and his son needed a break, having spoken to so many people from other organisations that they felt overwhelmed and didn't know who could help them. The matter was referred to a carer support advisor who spoke to Samuel the following day. The carer support advisor reported that Sarah was in denial about her diagnosis, that he cannot mention it and it was therefore very difficult to put any support in place. Samuel said that he was coping well, but that he did not have a good quality of life. It appeared to the carer support advisor that he would rather do everything himself rather than risk upsetting Sarah.

14.2.47 ***Hertswise (Age UK Herts):*** Hertswise received a referral from Carers in Herts, and the referral suggests that Samuel had difficulty coping with his wife who does not accept she has dementia. It is also noted that Samuel was close to 'carer breakdown'. Hertswise attempted to make contact and there was some liaison between Hertswise and Carers in Herts and the

[6] COGS- Weekly sessions for people with mild to moderate dementia. They provide five hours of social activity and friendship through a combination of cognitive stimulation, music, reminiscence, and orientation. Source: Dementia Services - Cogs Club / Age UK Dacorum (Accessed Jan 21)

notes reference Samuels medical appointments as perhaps explaining why he had not been available.

14.2.48 ***Carers in Hertfordshire:*** The carer support advisor then spoke to Samuel's son who explained that Sarah was refusing to accept her condition and did not see the effect on Samuel. As Sarah did not go out of the house, Samuel was unable to go out either. A request was made to refer the case to dementia nurses, that was followed up that day, with a referral to Admiral Nurse Care (ANC) via Hertshelp.

14.2.49 ***Crossroads:*** On the 15th August Crossroads receive an initial referral from Carers in Hertfordshire, that was subsequently chased on the 10th September before they undertook a telephone assessment on the 16th November.

14.2.50 ***ACS:*** On the 16th August Samuel attempted to speak to a CCO in ACS. Whilst a call was returned and a message left, they did not speak that day and the CCO went on leave shortly after

14.2.51 ***Admiral Nurse Care (ANC):*** On the 17th August, ANC phoned Samuel and left a voicemail. There was no further contact until September when Sarah's daughter phoned them.

14.2.52 ***ACS:*** On the 19th August, Ann emailed ACS questioning how a social care needs assessment might benefit her parents. She complained that nothing had happened. She also explained that her father has a significant health issue and that she was investigating "NHS Continuing Healthcare" but GP knew nothing about it.

14.2.53 ***GP Practice:*** On the 23rd August GP records show that Samuel had been newly diagnosed with diabetes and was seen again on the 29th August for a further review. During consultation it was noted that Samuel declined anti-depressant tablets or counselling for the time being.

14.2.54 ***Hertfordshire Partnership University NHS Foundation Trust (HPFT):*** On the 24th August a dementia support worker from the Alzheimer's Society phoned Samuel for a post diagnosis support call. Samuel explained that he had a very supportive daughter and that he had applied for an attendance allowance (AA) and a blue badge He also said he had had a carers assessment from Adult Social Care that he found useful. The EDMASS pathway was explained again, and verbal consent was given to refer to the Alzheimer's Society.

14.2.55 ***GP Practice:*** On the 24th August Ann contacted the GP regarding a continued healthcare assessment for Sarah. She was advised this was undertaken by social services.

14.2.56 ***Hertswise (Age UK Herts):*** On 31st August, Ann emailed Hertswise and asked about an SMI (severely mentally impaired) form that had been received. It was concluded they had been sent a DFG (disabled facilities grant) form.

September

14.2.57 ***ACS:*** On the 5th September the allocated social worker on returning from leave replied to Ann's email, asking for clarity regarding the type of support needed.

14.2.58 ***ANC:*** Following a 'self-referral' by Ann on the 10th September, Carers in Hertfordshire/ANC contacted Samuel on the phone before conducting a home visit on the 12th with both Sarah and Samuel. During the phone call, it was noted that Samuel was getting confused with all the different agencies who were engaged with him. He also said that he had not heard from the dementia nurses, despite a referral on the 15th August. Carers for Hertfordshire made enquiries regarding the referral to dementia nurses who reported having tried to phone Samuel

twice, but not getting a reply. The details of this conversation were then emailed to Samuel's son, outlining the conversation, the referrals that had been made and outlining a degree of confusion expressed by Samuel.

14.2.59 ***ANC:*** During the visit on the 12th, Samuel appeared anxious, and he was struggling with managing his wife's irritability but would not expand upon this as found it difficult to speak as his wife was in the other room. However, he reported that they feel they currently have enough support in place and feel they are coping well. They were reminded of the nurses contact details. It was subsequently noted that ACS asked that ANC did not make direct contact with the family as the main agencies involved were ACS, community mental health nurse and the hospice.

14.2.60 ***ACS:*** Later that day there was an internal email saying that daughter's observations of the meeting did not reflect how well Samuel and his son had engaged in their discussions. It was noted there were concerns over misinformation or misunderstanding and that the family were resistant to any support offered for which there was a charge. At this point, it was reported that a carers assessment had almost been completed, but they were waiting a call from Samuel to confirm if he wanted to be referred to a support agency, Crossroads.

14.2.61 ***ACS:*** On the 14th September ACS received an email from daughter asking social care to clarify why the need for a full social care needs assessment. She requested support to apply for NHS Continuing Healthcare, and asked what would be involved in this process and what help they might receive. She reflected on another family members experience and complained of finding it confusing knowing who to approach about what and requested advice. She said that David was trying to organise nurses through Carers in Herts and asked for information regarding the Sitting Service. She also explained that Sarah had attended a local Cogs club, but her condition was deemed to be too advanced. ACS replied to this email the following day, saying that a senior social worker had been arranged to assist completing the continuing healthcare (CHC) checklist.

14.2.62 ***ACS:*** On the 16th September, Ann emailed Adult Care Services saying she was disappointed with an ANC visit, who offered advice as opposed to practical help. Ann explained that her father 'has virtually given up trying to get help'. Ann said that she was trying to encourage him to try and access help via CHC and that he had asked to meet social care regarding accessing NHS continuing care. She continued that 'Dad is very unhappy, depressed and lonely'. She asked, 'Any help you can suggest would be great.' A visit subsequently took place on the 2nd October.

14.2.63 ***Hospice of St Francis:*** On the 18th September, Hospice of St Francis physiotherapy assessed Sarah's mobility, offering an exercise plan that was welcomed. She declined the offer of a walking frame. Samuel was offered a carers assessment that was declined. Samuel reported later that month, Sarah was not doing her exercises and concluded that her deteriorating dementia was contributing to this. Additionally, their son David emailed HosF and explained that Samuel was finding the situation difficult to cope with. Arrangements were made for a family meeting to take place in October.

14.2.64 ***EDMASS/Alzheimer's Society:*** The Dementia Support Worker contacted Samuel. Samuel explained that they had been given a blue badge, did not report any additional needs and was again asked about his consent to pass details to the Alzheimer's Society. The records note, the discharge from EDMASS and transfer to the Alzheimer's Society. A formal letter copied to the GP was sent from the EMDASS team, outlining support provided including telecare solutions, the benefits of having a carers assessment and that a referral to a Community Care officer from Social Services had been accepted.

14.2.65 ***Hertswise (Age UK Herts):*** There were a number of contacts between Hertswise and Samuel in September. On the 19th September Samuel explained that Cogs was not working, and he sounded depressed and was struggling to cope. It was also observed that he could not speak freely as he was overheard by Sarah. Arrangements were made for a home visit on the 26th.

14.2.66 ***Hertswise (Age UK Herts):*** On the 26th September a home visit was conducted, and details were recorded of Sarah's deteriorating condition. Samuel was becoming more anxious, worrying about Sarah, and explained he was not able to get a break, though his son attended one evening a week and on Saturday. He said that he had considered respite but felt guilty. He did agree for Hertswise to visit again and try to engage Sarah and give him a break.

October

14.2.67 ***ACS:*** On the 2nd October, ACS conducted a home visit to complete a CHC checklist. Samuel expressed discomfort answering questions in front of his wife. It was agreed that the checklist would be left for them, with a view to a social worker completing with information from the family. Later that day, Ann contacted ACS by email and was critical about the meeting. She explained that having read the NHS CHC guidelines, she believed that Sarah was eligible for Fast Track CHC because her "health is deteriorating rapidly" and she is "nearing the end of life". She listed a number of reasons for the CHC criteria being met as: -struggling to eat and her ability to swallow is going, - she cannot toilet, wash, or dress unaided, her level of comprehension had diminished, - losing the power to speak, - imagining people and events. Ann stated the Hospice told them vascular dementia is a terminal disease which usually ends when sufferers can no longer swallow. To resolve any confusion in communication, the family were invited to participate in meetings in relation to their parents' care and support either face to face or using facetime so that daughter could be present from her home abroad.

14.2.68 ***Hertswise (Age UK Herts):*** On the 4th October Hertswise visited, and it was reported that Sarah had not had a good night owing to her condition. No respite took place for Samuel and a further visit was arranged for later in October.

14.2.69 ***ACS:*** The following day, an advanced social care practitioner emails David explaining that as a self-funder, they had the option of securing care via the local authority at local authority rates or going down the private route. An offer was made for a meeting the following week. David replied, saying that they were taking small steps moving from respite to permanent care.

14.2.70 ***Hospice of St Francis:*** On the 4th October, the Hospice of St Francis hosted a family meeting with Samuel, Sarah, and David. The family explained why they concluded that Sarah's condition was deteriorating, including her not sleeping and not having insight into her own care needs. The family asked for one night a week respite overnight and day care at the Hospice and HoSF explained that this will involve other agencies that have a secure environment for people who may be prone to wandering. David expressed frustration that the Hospice could not cater for his mother, explaining that his mother had been at the forefront of supporting the building of the Hospice. Samuel said that he knew a neighbour who does care work in the home privately and that he may contact them. The HoSF contacted ACS who explained that the family do not fall within the threshold for care funded by the local authority and that they had provided the family with a list of agencies. The outcomes of the meeting were to liaise with ACS, to refer Sarah to telecare services and speak to the consultant and senior care staff at the Hospice.

14.2.71 ***ACS:*** On the 5th October 2018, ACS received a referral from Hospice of St. Francis stating that son was again requesting urgent respite for his father; a list of care agencies and care homes was sent to son.

14.2.72 ***ACS:*** On the 8th October, ACS replied to Ann explaining that they had hoped to complete a CHC checklist, but this proved too distressing, and we were asked to stop. It had been agreed that a further conversation would take place, to complete the outstanding questions. It was further outlined that the criteria for a full CHC assessment was met but a psychiatric nurse has to complete the full assessment to determine funding entitlement and that the criteria for fast-track are that the person in a rapidly declining condition with around three months to live as diagnosed by a doctor. If eligible FastTrack applications are completed by NHS not Social Care staff. GP will need to refer to the palliative care team for CHC fast-track. The notes also record that the CCO offered to complete a carers assessment and the option of a sitting service that would provide a few hours break for Samuel to go out. Both were declined and Samuel said he was considering asking for a neighbour to provide a 'sitting service'.

14.2.73 ***ACS:*** Ann responded to the email saying she was not aware of the 3-month expected life criteria re fast track CHC and asked for a copy of this clause. She complained that the CHC checklist had been seen as cruel and insensitive. She ended by writing "I would appreciate your urgent reply so that we may finally get my parents the help they need, and for which they have worked and paid taxes all of their lives."

14.2.74 ***ACS:*** That same day, an internal email from a manager suggests that communication ought not take place by email and that a conference call would be the best way forward. Further internal email traffic observed that the meeting with Samuel had gone well and his son, both having been very engaged in their discussions. It was noted there were concerns over misunderstanding and that the family were resistant to any support offered for which there was a charge. At this point, it was reported that a carers assessment had almost been completed, but they were waiting a call from Samuel to confirm if he wanted to be referred to a support agency, Crossroads.

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14.2.75 ***ANC:*** That same day ANC returned a call to HoSF who explained they were not a suitable service as they were not dementia specialists.

14.2.76 ***GP Practice:*** On the 16th October, the GP conducted a home visit following a call to the surgery. Sarah had been more confused and very restless at night. The notes states that there was a need to look at social services involvement and this was confirmed later that same day on a separate entry on the chronology.

14.2.77 ***ACS:*** A meeting was arranged for the 18th October at Sarah's home with the senior social worker from ACS and clinical director from St. Francis Hospice to discuss the most appropriate resources to meet Sarah's care and support needs and to clarify the continuing healthcare process from the hospice perspective. The meeting was cancelled by son, and the rearranged for the 24th but could not be attended by ACS. The outcome of the meeting is not known.

14.2.78 On the 19th October, Sarah and Samuel's daughter made the first contact with Ashlyn's Care Home, making an enquiry about fees.

14.2.79 ***ACS:*** On 23rd October, Sarah's social worker introduced herself by email to David, offering a skype conversation with him, Ann, and Samuel, to offer support and talk through the complexities of the funding.

14.2.80 ***Hospice of St Francis:*** On the 24th October HoSF conduct a 'Review' meeting at the home address. ANC and the social worker were unable to attend. David and Samuel were present and explained that Samuel was not getting rest at night owing to Sarah being unsettled. Samuel said he was not ready for overnight respite but would like respite in the day. Following the meeting, the Hospice consultant discussed night sedation such as zopiclone with the geriatric consultant and GP. This was agreed as appropriate and was to be followed up by the GP. HoSF emailed David about this a week later. The outcomes of this meeting were a letter

that was sent to Sarah's son, copied into Sarah's GP and Adult Social Care. This letter included a suggestion for day care at a dementia care home, advice regarding sleep hygiene, the follow up in respect of medication noted above, and a carer to help Sarah get up in the mornings that Sarah's son was to follow up.

14.2.81 ***Hospice of St Francis:*** On the 26th October Hertswise conducted a 2nd home visit. Samuel was able to leave for 15 minutes only. A follow up call was made on the 29th and Samuel explained that EDMASS and ANC were no longer involved. He explained that Crossroads had been to carry out an assessment, but he had put them off, as his daughter was back in the country.

14.2.82 ***Care Home:*** On the 30th October, Ann visited the local care home and informed them of Sarah's dementia. She was placed on the waiting list.

14.2.83 ***GP Practice:*** On the 31st October, Samuel had a consultation with a nurse at the GP practice. The nurse noted that Samuel was anxious to get back home to his wife who had dementia and had been left alone at home. The notes say he was very stressed.

November

14.2.84 In November the level of contact with the care home increased, the Hospice of St Francis continued to be engaged as did the GP.

14.2.85 ***Care Home:*** The care home carried out an assessment of Sarah which took place on the 2nd November when it was confirmed they could meet her needs. A few days later a room became available, that was subject to family discussions as they wanted a courtyard room. There was further communication in mid-November, when Sarah's son David emailed saying that Samuel was having difficulty coping. On the 20th November, Samuel had a private meeting with the manager and explained that he did not know how he was going to cope. The manager said that if he could not cope without Sarah, then he would need additional help at home.

14.2.86 ***Hospice of St Francis:*** The Hospice of St Francis maintained contact with Samuel and his son throughout November, with a total of nine contacts. Many of the contacts were unremarkable and supportive. Others indicate progress or otherwise such as on the 6th November it was reported that the sleeping medication appeared to be working well, and that a carer visiting once a week appeared to be working well. Towards the end of November, on the 20th it was noted that Samuel was struggling to care for his wife.

14.2.87 ***ACS:*** On the 2nd November 2018 another referral for urgent respite care was received by ACS from the Community Palliative Care Clinical Nurse Specialist. Son, relayed to her that his mother was deteriorating daily and despite day-care being considered this service may no longer be suitable as long-term care was now being considered as the next step.

14.2.88 ***ACS:*** On the 5th November 2018, ACS contacted son offering to commission respite care through ACS and she explained in detail the council charging policy and the options available. A meeting was suggested but was declined by son stating that a private care package had been sourced and was working well and that the plan was to gradually source 24-hour care privately for his mother.

14.2.89 ***ACS:*** Nearly two weeks later David replied by email explaining that Samuel was making gradual progress towards respite and inevitably permanent care. He also explained that a carer had started and was staking over some of the duties for Sarah and they were looking to increase the carers hours. David thanked ACS for the support.

14.2.90 ***Crossroads:*** On the 16th November a telephone assessment is undertaken during which Samuel discloses how sensitive Sarah is about her dementia diagnosis. It was explained at this point that they were entitled to 18 hours free care. A home visit was then conducted on the 20th and a care plan and risk assessment were completed.

14.2.91 ***GP Practice:*** On the 19th November Samuel saw the GP and explained that he did not think social services had been very helpful and he was advised to speak to Carers in Hertfordshire for assistance in navigating the system. A week later on the 26th, Samuel called the GP and explained that Sarah had been delirious for the last two nights, refusing to get dressed and was having issues with day-to-day personal needs. The GP visited, who noted Sarah was suffering from chronic confusion. In addition to medication, she was referred to the Holistic Healthcare Team (HHT) to avoid hospital admission. The notes anticipated them starting the same day.

December

14.2.92 ***ACS:*** On the 6th December, ACS make a 'ceasing note', in effect noting active involvement with the family. It was noted that Sarah had and more than £23,250 in savings so the family have arranged private visiting carers. They were advised to contact ACS once savings approached the threshold. The CHC checklist was discussed with Samuel, but he did not want to complete this. The family are aware that GP, Hospice of St Francis, and ANC were not of the opinion that Sarah met the criteria for fast-track funding.

14.2.93 ***Care Home:*** On 6th December, Sarah and Samuel's son confirmed a proposed date for Sarah to move as the 27th March. Later that month, on the 27th December, Samuel visited and was tearful, seeking reassurance about when he could visit Sarah once she moved in. He was told anytime.

14.2.94 ***Hospice of St Francis:*** On 13th December, David phoned the HoSF, explaining that Sarah was unable to recognise Samuel any longer. They planned to arrange a meeting for January.

14.2.95 ***West Hertfordshire Hospital NHS Trust:*** On the same day, Samuel was referred to the surgeons regarding a hernia. It was documented that he was extremely anxious about the risk of complications. Ultimately it was deemed that surgery was not required.

14.2.96 ***Crossroads***: On the 27th Samuel was called to offer a start date of service. He asked to put things on hold as daughter is over from Australia and wait until after 24th January 2019 as this is when daughter returns to Australia.

2019

January

14.2.97 ***Carers In Hertfordshire:*** On 2nd January it was reported by Samuel that matters were 'ok' at the moment, but when a carer support advisor spoke to Ann, she said that Samuel was not coping at all, was quite tearful and stressed and had lost a significant amount of weight. Ann explained that they were visiting a home and explained that they had not been offered the support needed as Samuel had not been truthful about how difficult the circumstances were. At the end of January, Ann informed them of the decision for Sarah to move into a care home.

14.2.98 ***Hospice of St Francis:*** On the 3rd January during a call between HoSF and an ANC, it was noted the family were of the view they had not been offered help, but that day care and respite had been offered by ACS, but Samuel had reported the time was not right for help.

14.2.99 ***Care Home:*** In mid-January, Ann visited Ashlyn's and subsequently Sarah attended for an assessment to be undertaken. Sarah also visited a friend who was staying at the home. The assessment determined that Sarah did need a dementia environment owing to night wandering and she was placed on the waiting list.

14.2.100 ***Crossroads***: On the 21st January they sent a welcome folder out in advance of commencing their service. On the 24th, Samuel phoned and asked to postpone the service until his daughter had returned abroad that was now planned for March.

February

14.2.101 In February there was limited agency contact, with a request made by the GP to Hertfordshire Community NHS Trust Bladder and Bowel Service, for pads that was followed by an exchange of calls between Samuel and the trust regarding suitability of equipment that was concluded satisfactorily, with no relevant commentary outside this service.

14.2.102 ***Alzheimer's Society:*** On 1st February, the case was closed, as there had been no response to a letter 4 weeks previously.

14.2.103 ***ACS:*** On 19th February, there was further email traffic from Ann to ACS, where she asked that if Samuel was still on a list to attend a course 'Partners Going into Care', to please cancel this as they were in the process of visiting care homes and had visited a local home on a number of occasions. She said that she had not mentioned the course to her dad at this point. Ann explained that they were waiting for a bed at this particular care home and that this was a care home that she was quite familiar with.

14.2.104 ***Carers In Hertfordshire:*** An assessment took place via phone call on the 26th February, when times and requirements were established.

14.2.105 ***Care Home:*** On the 27th February Ashlyn's offered Sarah a room. It was not a courtyard room and so Ann asked if there were a timeline for a courtyard room. She further outlined some important dates coming up, such as Sarah and Samuel's wedding anniversary on the 1st March and Samuel's birthday on the 14th April. She said she'd prefer to wait until after the 1st March.

March

14.2.106 In the last month of their lives, Crossroads Care, Hospice of St Francis, and the Care Home were the only agencies actively engaged with Sarah and Samuel.

14.2.107 ***Care Home:*** On the 5th March David contacted the home and explained that Ann had returned to Australia, and he had been left with the responsibility. He enquired if there were any possibility of getting Sarah in more promptly as Samuel was finding it difficult to cope. Later on, they phoned and said that a courtyard room would be available in the next two weeks. David asked if arrangements could be made more promptly, as it would enable him to spend time with his father at home, before he went abroad at the end of March. He was concerned at leaving his father alone to care for Sarah.

14.2.108 ***Crossroads:*** On Friday 8th March, a successful respite visit by Crossroads took place, but the carer fed back that Samuel was uncertain as to what the carer was doing there. Samuel asked her to leave a little early. Over the following two days, notes refer to Samuel only wanting help on Friday afternoon's and also preferring to wait for a permanent/consistent member of staff when he was informed that the member of staff who had visited had left the organisation.

14.2.109 ***Care Home:*** On 13th March, Sarah visited a friend at Ashlyn's and whilst she was visiting, Samuel explained to the manager of Ashlyn's that he was upset and feeling guilty. The manager did say there were options of a 'live-in' carer and Samuel said that their home was too small, and Sarah would not cope with someone else living in the home. A few days later, Ashlyn's contacted David and asked what date Sarah would be moving in. It was confirmed as being the 27th March. David said he would give his dad a reminder, that whilst Sarah was doing well at the moment, her condition could deteriorate quite quickly.

14.2.110 ***Crossroads:*** On Friday 15th March. A carer had been due to visit Sarah and Samuel. Crossroads phoned and told Samuel that they would be unable to provide cover and there would not be a visit that day. A few days later on the 19th, Crossroads spoke to Samuel again and explained they did not have anyone for a Friday visit. He was offered alternative dates but said he would prefer to wait for a Friday. He was placed on a waiting list.

14.2.111 ***Hospice of St Francis:*** On the 18th March, Hospice of St Francis phoned Sarah's son and then Samuel. Her son reported that Sarah was due to go into a care home, but that Samuel was not yet ready for her to go. Samuel himself said an agency was providing care and that all was fine.

14.2.112 ***Care Home:*** On the 20th March, Sarah and Samuel visited Ashlyn's again. Sarah visited a friend and Samuel spoke to the deputy manager. He asked about visiting times and explained that Sarah had become incontinent and sought reassurance that the home could cope. He also said that he had not yet completed the contract. He became very upset and started to cry. The following day, they visited Ashlyn's again and collected a friend and went for a meal before returning later.

14.2.113 Later in March Sarah is murdered by Samuel, and he then takes his own life.

15. OVERVIEW

15.1 GP

15.1.1 Sarah and Samuel had been registered at the same GP practice for many years, having been known to their GP for thirteen years.

15.1.2 During the first year of the relevant the period, the GP was the only agency working with Sarah and Samuel, where attendance may be considered routine in nature for a couple of their age. There was reference to Sarah's cognition, however it was reported that she remained active and sociable. It wasn't until December 2017, following a fall at home that the levels of intervention and referral from the GP escalated.

15.1.3 Following the fall, the practice referred Sarah to HPFT, specialist memory clinic (EMDASS) where she was subsequently diagnosed with vascular dementia. Through 2018, she was regularly seen at the surgery and at home, following episodes of dizziness.

15.1.43 The practice also referred Sarah and Samuel to Carers in Herts at the start of 2018, and also engaged with the Hospice of St Francis and Adult Care Services to assist the family.

15.1.5 During 2018, Samuel was also seen regarding a number of physical ailments and his GP noted that he had 'low mood' but was not depressed. When seen by a nurse at the practice, they recorded that he was very stressed. Sarah and Samuel's daughter, Ann also spoke to the GP reporting on two occasions that Samuel was having difficulty coping.

15.2 West Hertfordshire Hospital NHS Trust

Sarah

15.2.1 Sarah had been known to the trust for some physical condition associated with her age, before being admitted in December 2017 via A and E following a fall at home. This related to a collapse at home linked to her diagnosis of vascular dementia. During the assessment process, it was noted that a social care input was required, and that Samuel was at risk of 'carers burden' that is defined as the all-encompassing challenges felt by caregivers with respect to their physical and emotional well-being, family relations, and work and financial status (Pearlin et al., 1990)[7]. Their family were keen to support and acknowledged that they had struggled to persuade her to accept help. Following immediate treatment and discharge, she underwent further treatment for physical ailments before being seen in July 2018 by an elderly care consultant regarding her night-time light headiness. Changes in medication and other advice resulted. She was not seen again.

Samuel

15.2.2 Samuel had been known at the trust through the routine monitoring of prostate cancer. He also underwent further tests owing to generally feeling unwell and light headiness. No additional treatment resulted. It was recorded that he was the full-time carer for his wife and sometimes suffered from low mood and his GP had advised him starting on a low dose of anti-depressant.

15.3 Carers in Hertfordshire

15.3.1 Carers in Hertfordshire (CinH) provides advice, information, and support to unpaid carers - people looking after someone who is elderly, disabled, has a physical or mental illness or who misuses drugs or alcohol.

15.3.2 Their first contact was in February 2018 following contact by Samuel and Sarah's GP. Samuel was informed of available services but declined these. It wasn't until August that Samuel spoke to Carers in Herts (CinH) again, asking about respite care that resulted in referrals being made to Hertswise, Crossroads and ANC.

15.3.3 In August and September, both Sarah's son and daughter spoke to CinH asking for ANC. CinH followed this up and ANC made a home visit on the 12th September. This was the only visit undertaken as ACS subsequently advised that the family were finding all the organisations involved confusing and that the key agencies involved were ACS, community mental health nurse and the hospice.

15.3.4 There are no further notes on record of inter-agency communications until a fuller update was noted on the 5th November, when the Specialist Nurse updated regarding Sarah's deteriorating condition and the request for urgent respite. The case was closed to ANC as their input was no-longer required.

15.3.5 In January 2019, there was some communication in respect of Crossroads services conducting a trial visit later that month. Samuel had painted a picture of getting support from his daughter and yet, she described a different picture of Samuel losing weight and finding it difficult to cope. The advisor contacted ANC who advised that the family were refusing help and focusing on getting a residential placement. Later that month, the CSA spoke to the daughter and sent details for the Care Choice website as a reference point for sourcing care.

[7] Source: https://www.sciencedirect.com/topics/medicine-and-dentistry/caregiver-burden (Accessed August 2020)

15.4 Hertfordshire Partnership University NHS Foundation Trust

15.4.1 Hertfordshire Partnership University NHS Foundation Trust is responsible for EMDASS. The service provides assessment and diagnosis of dementia. For those people diagnosed with dementia a period of post diagnostic support is provided by the Alzheimer's Society offering service users and carers the opportunity to plan for their future. This service is delivered in partnership with the Alzheimer's Society for a period of 38 weeks in total, after which the care is transferred to the individual GP and the service user could be referred into the Alzheimer's society community dementia Support Service.

15.4.2 In February 2018, following a referral by the GP Sarah undertook Addenbrooke's Cognitive Examination (ACE III). The ACE III is a cognitive test that assesses five cognitive domains: attention, memory, verbal fluency, language, and visuospatial abilities, scoring 9/18, 8/26, 3/14, 21/26 and 10/16. It was noted there had been a gradual decline in her memory and memory was patchy. An older age consultant psychiatrist recorded a diagnosis of Subcortical Vascular dementia and wrote to the GP. Details were also passed to the Alzheimer's society and a memory nurse was allocated. The memory nurse was allocated from the 5th February through to the 5th June, the majority of post diagnosis support being provided by Dementia Support Worker's from the Alzheimer's society within the EMDASS Support Team.

15.4.3 No contact was made by EMDASS to Sarah and Samuel between 5/02/18 and 04/06/18 as they weren't identified as high priority and owing to a waiting list for post diagnostic support.

15.4.4 Samuel was signposted to the county council for a blue badge and also to Hertswise for information and support regarding attendance allowance. It was noted that he felt exhausted and stressed at times.

15.4.5 Further contact was made in June through to September when telecare equipment was discussed and Samuel's application for a blue badge. In September the Alzheimer's Society transfer document was completed and a discharge letter was sent summarising services offered and information provided including; - Provision of 'post diagnostic information packs'; - NHS 8-week memory group-declined; - information regarding Telecare solutions; - information re benefits entitlements; - Alzheimer's Support.

15.6 Hertfordshire Community NHS Trust (Community Therapy and Bladder and Bowel Service)

15.6.1 Sarah had been originally referred on the basis of a number of falls and was accepted for a community occupational assessment. A further referral was made by the GP in respect of the bladder and bowel service.

15.6.2 Following a home visit in January 2018, Sarah felt she did not need any equipment, whilst Samuel and their daughter felt some equipment may be useful and a referral was made to Adult Care Services to provide rails to the front and back of the premises and other equipment such as an over bed table and pendant alarm. They also asked for 'covers' for kitchen cupboards to be researched owing to reports of Samuel banging his head. They noted that Samuel completed all domestic activities.

15.6.3 Over the following few months, Samuel cancelled some of the equipment ordered and advised that he had arranged for rails to be put up. Further engagement related to provision of sanitary provisions and Sarah was discharged from the service in February 2019

15.7 Adult Care Services

15.7.1 Sarah first came into contact with ACS in January 2018 following a referral for handrails to be fitted. On speaking to Samuel, he explained how difficult Sarah was finding dealing with all the professional's assessment and for him to talk in front of her. There was a gap until in contact until June 2018 when Samuel had been referred for a carers assessment on information that he was struggling to cope. He declined the assessment as he said he was coping well. His description of how he was coping as opposed to how his family saw him coping became feature of their interactions.

15.7.2 A carers assessment was completed in July, when the first of many conversations in relation to financing for care took place. Over the following months, ACS engaged with both Sarah's son and her daughter as well as Samuel, where a theme of discussion was the criteria for continued healthcare funding. It seems that Sarah and Samuel had savings in excess of a threshold, meaning that they had to pay for care. During this time, Sarah's daughter reported how 'unhappy, depressed and lonely' Samuel was becoming.

15.7.3 The relationship between ACS and the family became tense, with Sarah's daughter communicating via email as she lived in Australia and not being able to take part in some of the conversations. ACS sought to overcome any miscommunications by offering 'virtual' meetings.

15.7.4 In October 2018 an attempt was made for a multi-disciplinary meeting with the Hospice of St Francis that was cancelled by Sarah's son and ACS could not attend the rescheduled meeting. ACS do not have details of the outcome of the rescheduled meeting.

15.7.5 In November 2018, further requests were received for urgent respite care and ACS offered to commission the services for the family. There was continued communication with the family until the 26th February via email in respect of care and accommodation for Sarah.

15.8 Hertswise (AgeUK)

15.8.1 Hertswise is a countywide service designed to support people living with dementia, low level memory loss or mild cognitive impairment as well as their loved ones and carers. It aims to ensure that people of all ages, living anywhere in Hertfordshire, are able to easily access information and advice, activities, and support regardless of whether they have (or want) a diagnosis. The service is delivered by a partnership of community and voluntary groups, including Age UK Hertfordshire, Hertfordshire Independent Living Service, Herts Mind Network, and Carers in Hertfordshire.[8]

15.8.2 Hertswise's initial contact was instigated by Sarah's daughter in January 2018 when she outlined Sarah's condition and that her father can be stubborn and not welcoming help. In February he declined help and there was no further contact until June when EDMASS referred Sarah. Samuel then spoke to Hertswise, and he explained how upset Sarah became when talking about dementia and there was a discussion about attendance allowance forms. During conversation he explained how Sarah's condition had progressed, with difficulty washing and dressing and generally needing reminding. Hertswise engaged with Sarah's daughter who described her father as struggling looking after an 82-year-old with dementia.

15.8.3 In July, Hertswise visited to complete forms and made follow up calls to Samuel and their daughter noting that a carers assessment had been completed, benefits checks completed and registered Samuel as a carer at the local library. There were also further discussions about crossroads providing a sitting service they visited and helped to complete an AA form.

[8] Source: About us – Hertswise (Accessed December 2020)

15.8.4 In mid-August in a referral from Carers in Hertfordshire, requested advice on caring for Sarah and observes that Samuel is close to carer breakdown, having difficulty managing the situation and Sarah does not accept her diagnosis. This strain is further referenced in September with Samuel sounding depressed and struggling to cope before a home visit on the 26th September. At that visit, it was noted that Sarah sometimes doesn't recognise her husband and does not wash or dress herself. He was advised to get in carers to help with bathing and to tell wife carer is a nurse. It was noted that he had considered carer's respite but felt too guilty although he was very stressed.

15.8.5 In October, two supportive visits were made that gave short periods of support to Samuel. The last contact with the family was in late October when it seems their daughter had returned to the UK for a period of time.

15.9 Crossroads Care Hertfordshire

15.9.1 Crossroads Care Hertfordshire North provides support for unpaid family carers and the people they care for in Hertfordshire.[9]

15.9.1 A referral was initially made on the 15th August 2018 before a telephone assessment and home visit on the 16th and 20th November respectively. Further visits were postponed until March at the request of Samuel as his daughter was in the UK from Australia.

15.9.2 A home visit was undertaken on 13th March and a staff member reported that Samuel seemed “very uncomfortable” about having someone in the house and was reluctant to leave his wife in her presence.

15.10 Alzheimer’s Society

15.10.1 The Alzheimer’s Society (AS) is commissioned to work in partnership with Hertfordshire Partnership Foundation Trust (HPFT) to provide post diagnostic support to patients who are diagnosed through the Early Memory Diagnostic and Support Service (EMDASS). At the time of the deaths of Sarah and Samuel AS were primarily recording their interactions on the HPFT records system. There is very limited commentary on the AS system.

15.10.2 In February 2019, Alzheimer’s Society Community Dementia Support team closed the case with Sarah and Samuel. They were given contact details of how to contact AS for further support.

15.11 Hospice of St Francis

15.11.1 The HoSF received initial referrals from the GP in July 2018 that resulted in an assessment in August, where it was noted that Samuel was supporting Sarah with some daily care tasks. During that initial assessment, Samuel declined a carers assessment. Shortly after Sarah received an initial physio assessment in respect of her mobility and was given an exercise plan, but declined offers of equipment.

15.11.2 Over subsequent months, it seems her condition deteriorated and the impact on Samuel became more pronounced, with Samuel reportedly not being able to cope. An initial family meeting with HosF, Samuel and the son took place In September 2018, and they made a request for one night a week respite at the local hospice which was adjacent to their home address and respite through day care.

[9] Source: Crossroads Care Caring For Life Hertfordshire Home (crossroadshn.org.uk) (Accessed January 2021)

15.11.3 In October, a joint professionals meeting took place. Present were the consultant, CNS, Sarah and Samuel and their son. Social care and ANC could not attend. Sarah's sleeping patterns were preventing Samuel from getting night-time rest and the hospice consultant spoke to the GP about night-time sedation that offered some respite to Samuel. The family were referred to telecare services and HoSF spoke to ACS who advised that Sarah did not meet CHC criteria. ACS had offered to organise respite at a care home, but Sarah had only wanted to go to one of two places including the hospice.

15.11.4 Over the period of September to December, it was reported that Sarah's condition continued to deteriorate and in December the son requested a meeting between HoSF, ACS, his sister and himself. It seems that the plan was for this meeting to take place in January but did not take place.

15.11.5 The HoSF chronology shows a number of efforts to work with Adult Care Services to source and signpost the family to places for support. It also shows that in discussions with Sarah's son, the amount of support Sarah had given to the hospice over the years was a point of discussion in seeking support. However, it was determined that a nursing home was more appropriate than a hospice for a patient such as Sarah.

15.12 Care Home

15.12 Sarah was known to the care home, for support she had previously given and also visiting her friends who had gone to live there.

15.12 Sarah's daughter made contact in late October 2018 making enquiries about availability. Sarah paid several visits, including to friends who were staying at the home and an assessment that took place in mid-January 2019. Most of the dealings with the family were via the daughter until she returned to Australia.

15.12 A room was offered in February that did not meet the family requirements for a courtyard room.

15.12 In early March, their son phoned and reported that Samuel was finding it difficult to cope. Soon afterwards a suitable room became available and was offered for occupation towards the end of March.

15.12 At this time, Samuel did speak to the care home on several occasions. He expressed guilt and was quite upset, and the care home did suggest there were other options such as live-in carers.

16. ANALYSIS

The analysis of this Domestic Homicide Review explores the reasons why events occurred, how and whether information was shared and, subsequently, whether the sharing informed decisions and actions taken

16.1 Domestic Abuse/Violence

16.1.1 This review commenced prior to the Domestic Abuse Act receiving Royal ascent in April 2021 and therefore relies on the former government definition. The passing of the Act and definition has not materially affected the review, analysis, or findings.

16.1.2 The Government definition of **domestic abuse** was: - Any incident or pattern of incidents of controlling, coercive, threatening behaviour, violence, or abuse between those aged 16 or over who are, or have been, intimate partners or family members regardless of gender or sexuality. The abuse can encompass, but is not limited, to the following types of abuse: psychological, physical, sexual, financial, emotional.

16.1.3 **Controlling behaviour** is defined as: - A range of acts designed to make a person subordinate and/or dependent by isolating them from sources of support, exploiting their resources and capacities for personal gain, depriving them of the means needed for independence, resistance and escape and regulating their everyday behaviour.

16.1.4 **Coercive behaviour** is defined as: - An act or a pattern of acts of assault, threats, humiliation and intimidation or other abuse that is used to harm, punish, or frighten their victim.

16.1.5 Sarah died as a result of a single, fatal act of violence perpetrated by Samuel before he took his own life.

16.1.6 In order to try and understand why this tragic event took place, the review panel considered events from a number of perspectives. These included whether; the events were part of a controlling, coercive pattern of behaviour that represents homicide as part of a predictable process involving domestic abuse; whether the events were spontaneous in that they occurred in response to a trigger event or if there was an 'emotional journey to homicide' that developed over time or whether Sarah and Samuel planned this end to their lives. In considering these notions, it is accepted that none are mutually exclusive.

Pattern of Abuse

16.1.7 The panel was not able to determine that there was a broader history of domestic violence or abuse to this single act. This is based on the information gathered by Hertfordshire Police, as well as provided by agencies, friends, and family. None of this information provides any evidence indicating that Sarah was the victim of a wider pattern of domestic violence and abuse perpetrated by Samuel. The information from friends and professionals suggests that Samuel was a devoted husband who doted on his lifetime partner.

Process/Homicide Timeline

16.1.8 In considering predictability, one theory, the eight stages contained with the Intimate Partner Femicide Timeline[10] was subject to discourse. It seemed that there were a number of features that may fit this theory, such as; Stage 4: Trigger warning signs; threat of separation, deterioration of physical and mental health; Stage 5: Escalation warning signs; Stage 6: Mental or physical health deterioration irreversible; Stage 7: Planning – buying weapons; Stage 8: Homicide. These factors seem apparent during the relevant period of the relationship, as opposed to being conclusive as to the predictability of events.

Spontaneous Crime v Emotional Journey

16.1.9 The review panel considered whether the events were spontaneous in that they occurred in response to a trigger event. That is not to say that the spontaneity requires that the decision to murder is followed by the actual act very swiftly, rather the decision is made spontaneously in response to the trigger event. There is substantive research[11] available that intimate partner

[10] Source: https://www.womensaid.ie/assets/files/pdf/jane_monckton_smith_powerpoint_2018_compatibility_mode.pdf (Accessed May 2020)

[11] Schlesinger 2002, Adams 2007, Monckton-Smith 2012

femicide is rarely spontaneous and the '[He] just snapped' explanation which suggests an immediate proximal provocation is not supported.

16.1.10 One theory put forward was that there was an 'emotional journey to homicide' that developed over time. In Samuel's case it is possible that he may have perceived his world as 'falling apart' over time, as well as feeling increasingly desperate at the thought of separation. After all Schlesinger describes 'catathymic homicides' as occurring when: *There is a change in thinking whereby the offender comes to believe that [he] can resolve [his] inner conflict by committing an act of extreme violence against someone to whom [he] feels emotionally bonded.*[12]

16.1.11 Whilst there is no information in this case to suggest a pattern of domestic abuse, there were a number of markers/triggers apparent, including separation owing to Sarah's failing health. In a publication 'Older women and domestic homicide', it specifically cites 'Separation is another common high-risk factor (DVDRC, 2018). Spouses who face being separated through circumstances such as hospitalization or a move to a long-term care facility are particularly vulnerable (Cohen and Molinari, 2010, Malphurs et al., 2001).[13]

16.1.12 The analysis of agency contact that follows will show how he was struggling to cope, and so there may have been a change in his thinking at a point in time. Moreover, the panel learned that they had just celebrated their Golden Wedding Anniversary, Sarah and Samuel's daughter had just returned to her home abroad, their son was due to go to work abroad and that Sarah was due to move into the care home. Each one of these events in themselves could be considered 'emotional' and so collectively, it is arguable there was significant emotional strain on Samuel.

Suicide Pact

16.1.13 Whilst the panel relied on the conclusions of the coroner, that Sarah's death was an unlawful killing and that Samuel's was one of suicide, they did consider a broader discussion point of a suicide pact, that is an arrangement that two or more people make to kill themselves at the same time and usually in the same place,[14] as a way of trying to understand why events occurred. After all Sarah and Samuel had been in a long and happy relationship for many decades.

16.1.14 There is very limited national or international research on the matter of suicide pacts. An Epidemiology of suicide pacts in England and Wales, 1988-1992, found that in 62 pacts, 85 people signed a note (69%) which is far higher than the 30-40% who take their own life alone.[15] This would indicate a degree of premeditation. This does little to assist our understanding in this case, as there is no evidence to suggest that Sarah had agreed with the course of action that Samuel undertook, and the panel acknowledge that Sarah's capacity to agree to such a course of action, would be questionable given observations made regarding her declining cognition This conundrum is subject to commentary in an article 'Domestic violence in later life' that considers the absence of a domestic violence history; 'This is largely unexplored territory where domestic violence and health issues overlap in ways that are quite specific to older couples. It is in these cases as well that a "mental illness, mercy killings, or suicide pacts" motive is often (problematically) proposed in official records and news reports. Roberto et al.

[12] Source: https://journals.sagepub.com/doi/full/10.1177/1077801219863876 (Accessed June 2020)
[13] Source: Older women and domestic homicide - ScienceDirect (Accessed April 2021)
[14] Source: https://www.collinsdictionary.com/dictionary/english/suicide-pact (Accessed June 2020)
[15] Source: Epidemiology of suicide pacts in England and Wales, 1988-92 | The BMJ (Accessed October 2020)

(2013), especially when one partner can no longer provide the extensive care required by the other. The wishes of the victim are often unclear and/or unreported'.[16]

16.1.15 In an article from Canada entitled 'Domestic Homicide and Homicide-Suicide: The Older Offender' examined data over a 15-year period in Canada. It found that 'Several victims had pre-existing medical illnesses, indicating that the offenses may have been committed by individuals who were caregivers to chronically ill spouses. At the time of the offense, most of the perpetrators had a mental illness, usually depressive disorder, but few had received psychiatric help. The impact of mental illness on domestic homicide-suicide is indicated, underscoring the importance of identifying existing psychopathology.'[17]

16.1.16 Nonetheless, given the limited research into cases of homicide-suicide, it is suggested further research may be helpful to identify features and assist learning for the future. However, plans for an online repository of all DHRs to go live by April 2022 are welcomed, enabling review panels to consider patterns, risk factors and broader learning.

> ***(LO1) Learning Consideration/Opportunity****: It is important that professionals are able to understand in similar circumstances those likely to be at risk and actions that agencies can take to reduce the likelihood of future murder/suicides. A single DHR is restricted in scope and research across a number of DHR's is required to deliver this understanding.*
> **Recommendation 1**: *The Home Office to consider further research into murder/suicide of cases of a similar profile, to develop an understanding and identify actions to mitigate the risk.*

16.2 Agency Involvement

16.2.1 In the period January 2018 to March 2019, there were eleven (11) agencies involved with Sarah and Samuel of which ten (10) were working with them during the period June through to August 2018. The only agency consistently involved, was Sarah and Samuel's GP, the remainder becoming involved at around the time of Sarah being diagnosed with dementia and/or when the symptoms of her condition became problematic. The intensity of agency involvement varied, as it did the purposes of that engagement.

16.2.2 The analysis of agency interaction that follows, will show the breadth of support that was and remains available locally in Hertfordshire to those living with dementia and those who care for them. This was recognised by the panel as positive.

16.2.3 The analysis of the chronology also revealed themes that are further explored within the individual agency analysis that follows. These include; - Support being declined; - Carer Stress; - Confusion for clients working with multiple agencies; - multi-agency working; - Continuing Healthcare Assessments

<u>Support Declined</u>

16.2.4 Notwithstanding the breadth of support available, this was often declined by Samuel. *(Examples include 14.2.20, 14.2.24,14.2.28, 14.2.32, 14.2.34, 14.2.39, 14.2.53, 14.2.58, 14.2.63, 14.2.72, 14.2.81, 14.2.88, 14.2.96, 14.2.100.)* Conversely, Sarah and Samuel's children were keener to receive support and pointed out early on, that Samuel would not welcome help

[16] Source: K. Roberto, B. McCann, N. Brossoie, Domestic violence in late life: An analysis of national news reports, Journal of Elder Abuse & Neglect, 25 (3) (2013), pp. 230-241, https://doi.org/10.1080/08946566.2012.751825 (April 2021 via Older women and domestic homicide - ScienceDirect

[17] Source: Bourget, Dominique & Gagné, Pierre & Whitehurst, Laurie. (2010). Domestic Homicide and Homicide-Suicide: The Older Offender. The journal of the American Academy of Psychiatry (Accessed May 2021 via researchgate.net)

(14.2.18). Reasons why Samuel declined support such as pride or not recognising his own need for support are explored at 16.6.9.

Carer Stress

16.2.5 He showed signs of carer stress, and his family described him on various occasions as struggling to cope and it was reported that he was at risk of carers burden *(14.2.9, 14.2.23, 14.2.30, 14.2.63, 14.2.65, 14.2.66, 14.2.83, 14.2.86, 14.2.97)* to some and said he was managing to others and continued to decline help, portraying a contradictory picture.

Confusion for clients working with multiple agencies.

16.2.6 Samuel said himself that he found the number of agencies confusing and that Sarah became confused with the number of agencies engaging with them. *(14.2.20, 14.2.24, 14.2.58, 14.2.60, 14.2.61, 14.2.62)* Cross referencing this with similar family observations about information, it is understandable to see how immediate family members may find it difficult to navigate the system and may feel overwhelmed. It is fair to observe that the panel acknowledge how complex the system appears.

Multi-agency co-ordination

16.2.7 The individual agency analysis within this section shows that notwithstanding the multi-agency engagement with Sarah and Samuel, there was limited co-ordination across agencies. That is not to say agencies did not communicate, but it was one agency to another agency, with only one attempt at a multi-agency meeting that was limited in nature and that some agencies could not attend.

Continuing Healthcare Assessments

16.2.8 It also appeared to agencies that notwithstanding the breadth of offer, 'Continuing Healthcare Assessments' became a point of discussion, with numerous linked entries on the chronology *(14.2.52, 14.2.60, 14.2.61, 14.2.62, 14.2.67, 14.2.72, 14.2.73, 14.2.77, 14.2.79, 14.2.92).* It is understood that continuing healthcare occurs "when your primary need is a 'health need', the NHS is responsible for providing for and funding all your needs, even if you're not in hospital".[18]

16.3 GP

16.3.1 A comprehensive chronology assisted the chair to interview one of Sarah's GPs and ask a number of follow up enquiries. Of the volume of contacts for both Sarah and Samuel, many were routine in nature, others linked to Sarah's dementia and in Samuel's case the impact of caring responsibilities was apparent.

16.3.3 Sarah was diagnosed with Vascular Dementia, a common type of dementia caused by reduced blood flow to the brain.[19] The GP explained that in Sarah's case, they were treating Sarah to prevent TIA's that is transient ischemic attack (TIA), or "ministroke". It is reported that Vascular dementia is the second most common form of dementia and is caused by reduced blood flow to the brain – usually from a stroke or a series of strokes.[20]

Routine Attendance Sarah

[18] Source: Am I eligible for NHS continuing healthcare funding? - Money Advice Service (Accessed May 2021)
[19] Source: https://www.nhs.uk/conditions/vascular-dementia/ (Accessed October 2020)
[20] Source: https://dailycaring.com/tia-is-a-warning-sign-of-stroke-and-vascular-dementia/ (Accessed October 2020)

16.3.4 There are nearly one hundred entries on the chronology relating to Sarah during the relevant period that include twenty consultations in person, including four home visits and twelve telephone consultations. Samuel was present at all home visits and from discussions with the GP he was always present at appointments at the practice. Their daughter was also present on occasion and made a number of enquiries of the practice.

16.3.5 Whilst there was nothing within the chronology to indicate domestic abuse featured in the relationship, the panel did consider the merits of 'routine enquiry' against the continued presence of Samuel during consultations, posing the question as whether his presence was as a supportive husband or controlling partner.

16.3.6 It was acknowledged there had been studies such as to the benefits of routine enquiry such as the Cochrane Report that found a two-fold increase in identification of domestic abuse, but also found that there was no increased uptake in accessing specialist provision and concluded there was insufficient evidence to justify implementation of IPV screening for all women in healthcare settings.[21]

16.3.7 Against this it was reported that there is an annual programme of training, appraisal and revalidation helps GP's respond effectively to patients who are experiencing or perpetrating domestic violence or abuse. The efficacy of this regime is supported by a recent Care Quality Commission inspection; "Staff knew how to recognise signs of abuse in vulnerable adults and children. Staff were aware of their responsibilities regarding information sharing, documentation of safeguarding concerns and how to contact relevant agencies in normal working hours and out of hours"[22]

16.3.8 On considering dementia and the prevalence of domestic abuse, there are limited studies on the subject. One article found, "an increased odds of domestic abuse among people with dementia vs those without".[23] However there are broader references, one suggesting "women with mental health problems are more likely to be domestically abused, with 30-60% of women with a mental health problem having experienced domestic violence".[24] The Home Office analysis of DHR's also reported "Mental health issues were present in 25 of the 33 intimate partner homicide DHRs". [25]

16.3.9 The GP also reflected on the question of routine enquiry for patients with mental health problems and considered that there was a learning opportunity for all practice staff to more often ask patients about domestic abuse. The question of disability and other protected characteristics is further explored at 16.15.5, but at this juncture, it is suggested that a proportionate response would be to consider concerns about mental health being a trigger for routine enquiry.

16.3.10 The majority of Sarah's consultations related to her memory loss, failing cognition and confusion. This first year within the relevant period, seems unremarkable, with no apparent need to engage with other agencies or making any referrals. In April 2017, cognition tests were undertaken, and the notes record that a referral to dementia services may be considered. However, Sarah and Samuel agreed that they would continue to manage the situation and seek further advice if required. This is considered good practice and reflects National Institute

[21] Source: Screening women for intimate partner violence in healthcare settings | Cochrane/ (Accessed October 2020)
[22] Source: Boxwell Road Surgery NewApproachComprehensive Report (GPPractices Location Apr 2016) INS1-1290502202 (cqc.org.uk) (Accessed January 2021)
[23] Source: A systematic review of the prevalence and odds of domestic abuse victimization among people with dementia - PubMed (nih.gov) (Accessed January 2021)
[24] Source: Mental health statistics: domestic violence | Mental Health Foundation (Accessed January 2021)
[25] Source: Home office - Domestic Homicide Reviews - KEY FINDINGS FROM ANALYSIS OF DOMESTIC HOMICIDE REVIEWS (publishing.service.gov.uk) (Accessed January 2021)

for Health and Care Excellence (NICE) guidelines, placing patients at the centre of decision making.[26] The remainder of 2017 was typified by unrelated medical matters.

16.3.11 It seems the first indication of Sarah's condition deteriorating occurred in December 2017 after Sarah had been admitted to hospital following a fall, Sarah was seen with Samuel and their daughter and was informed that she was likely to suffering from vascular dementia. Her referral to the memory clinic was normal and appropriate given the circumstances.

16.3.12 During the first six months of 2018, there were a number of consultations in relation to unrelated matters, but further reports of dizziness and another collapse during the night. (13th April 2018). The gravity of Sarah's episodes became more apparent, when on the 22nd June Samuel went to see the GP about Sarah. That same day the GP carried out a home consultation with Sarah in presence of Samuel and their daughter, it was noted that these episodes of dizziness and collapsing had been occurring for eighteen months. This consultation resulted in referrals to the TIA clinic, holistic care team and also the care of the elderly team. The GP explained that the holistic care team were a community team made up of nurses, physio and occupational therapist who could see a patient and carer at home for assessment of needs and support if necessary.

16.3.13 From July 2018 to September 2018, there were a number of administrative entries and consultations, when on the 20th July, Sarah's daughter informed the GP that Samuel was not coping and that a referral to the Hospice of St Francis was needed. This was acted on promptly and within three days the Hospice of St Francis responded stating 'they cannot offer a bed as Sarah was not end of life'. In addition, the GP also rang Adult Care Services and left a message, though there is no record of the call having been returned or there having been a conversation between the GP and social care.

16.3.14 Shortly after on 24th August, Sarah's daughter made enquiries regarding Continuing Healthcare Assessments and was signposted to district nurses or social services, a subject that became a point of contention for the family that is discussed under the ACS section.

Assessment and Diagnosis

16.3.15 The chair explored with the GP how (a) the deterioration of Sarah's condition was assessed over time and (b) the implications of Sarah's condition being determined as being at 'end of life' on the basis that the family had argued an entitlement with social care as Sarah was approaching that stage in her illness. The GP explained that GPs do not stage dementia, though the memory clinic would use the terms, mild, moderate, or severe. It is therefore difficult to attempt to assess Sarah's condition retrospectively when using the 'seven-stage' model often referred to by organisations working in this field.[27] However, the GP further explained that Sarah was not close to 'end of life', and that dementia unlike other illnesses, is not one where one can know that someone will die within a probable amount of time. As a GP, she had never declared a dementia patient as being at 'end of life'.

MDT meetings

16.3.16 On the 16th October following a multi-disciplinary team (MDT) meeting, a note was recorded on Sarah's records that Samuel was not coping. That day a GP carried out a home visit. Samuel explained that Sarah had been very sleepy for two to three days and increasingly

[26] Source: https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making (Accessed October 2020)

[27] The stages graduate from stage 1, where there is no cognitive decline through to stage 4 that is described as mild dementia, through to stage 7 that is severe dementia' Source: The Seven Stages Of Dementia (Accessed October 2020)

confused. Whilst it was noted that social services had seen them, and that they will have to pay for amenities, there does not appear to be any reference to Samuel, how he was coping and whether there was any medical support required. There is also no corresponding entry on Samuel's chronology.

16.3.17 On exploring MDT meetings with the GP, these used to be attended by palliative nurses (PN) from HoSF and district nurses and the community matron. These no longer take place in this format, though GP's do meet with PN monthly. Short notes were taken and added to the medical record if any action was taken. These notes are no longer available. These meetings were not led or chaired by anyone, rather provided an opportunity to share information. Considering what is known about the number of agencies working with Sarah, and with the benefits of sharing information to improve co-ordination, it seems that the loss of wider MDT meetings is an opportunity for further exploration.

16.3.18 In November (2nd and 19th), the GP had a conversation with the hospice, where they explained that there was a misunderstanding regarding respite and what the hospice may offer, and that they had been trying to encourage the family to work with social services support. Medication was agreed that would help Sarah sleep through the night and Samuel was advised to contact Carers in Hertfordshire service. On discussion, this is the locally recognised pathway for support. There is a corresponding entry on Samuel's records, with a note that he had come to see the GP mostly to talk about Sarah. This dual entry on two records is helpful, though not consistent throughout examination of the chronologies where entries relevant to Samuel are made on Sarah's notes (20/07/18 and 16/10/18). It is arguable that there ought to be some duplication, because whilst Samuel may have come to discuss his wife's condition, there was a time that in Samuel caring for Sarah, there was an effect on his mental health and well-being. In discussion with the GP, it was acknowledged that relevant information only should be written on a spouse's record, but sometimes may not always occur.

16.3.19 At a further home visit on 26th November, Sarah's confusion had reportedly deteriorated and there were issues regarding her personal hygiene. The notes show that that she was referred to the Holistic Homecare Team to avoid hospital admission. The GP records show that they would start that same day and the HoSF chronology shows that their holistic team spoke to Samuel. Samuel declined assistance and said he would contact them if he needed support. On the one hand it seems that Sarah's condition was so acute, to consider hospital admission and yet this support was declined. It is notable that Samuel declining help appears to have been a feature across a number of agencies and the GP reflected on this being a potential learning opportunity, seeking to understand why a carer would decline support. The subject of improved professional curiosity has subsequently been subject of work by Hertfordshire Safeguarding Adults Board, with a Learning Bulletin on Professional Curiosity[28] circulated across the partnership including GPs in October 2020, with further information planned for 2021.

Routine Attendance Samuel

16.3.20 Samuel had twenty-eight consultations, two of which were by telephone during the relevant period. Of these the majority relate to medical ailments that one may associate with his age. Whilst not directly linked, they are considered important, in that the breadth of physical ailments including suspected cancer and diabetes, combined with his caring responsibilities for Sarah are likely to have added to what his GP describes as 'health anxiety'.

16.3.21 Samuel's state of mind and depression became more apparent during 2018. On the 12th June 2018, it was noted 'gets low on some days, but not depressed'. The notes reference the option

[28] Source: Virtual School Higher Education college offer (hertfordshire.gov.uk) (Accessed March 2021)

of an anti-depressant if matters don't improve. Further entries or potential flags on his records became apparent in August such as; when seen by a GP it was noted that a loss of weight may be attributable to stress and that he was very tearful; on the 29th he was seen by the same GP including a further comment regarding weight loss being attributable to stress; 31st October during a consultation with a specialist nurse, he said that he was feeling "very stressed" and that he was keen to get home quickly as he had to leave his wife alone. We also know from Sarah's records that his daughter had said on 22nd July the same GP had said Samuel was not coping.

16.3.22 Following the appointment on the 31st October, consultations are routine and relate to a variety of ongoing physical conditions and no further reference is made as to Samuel's state of mind. Only two entries reference Sarah, the first on the 19th November where it was noted that he had come to mainly talk about his wife and on the 28th November, when the records state he had made an appointment for Sarah. On neither occasion or the other three appointments, was there wider note or observation in respect of health anxiety, or stress related to his caring responsibilities.

16.3.23 Considering the nurses entry on the 31st October, and how such observations are brought to the attention of the GP, it was explained there are two routes, either informally within the practice or by the nurse sending a 'Patient Task' attached to medical records. The patient task was not raised, nor can the GP recall having been alerted to this concern. Whilst Samuel was seen a few weeks later and no concerns were raised, the use of the 'Patient Task' process would have alerted the GP to the nurse's observation.

Assessment and Diagnosis Treatment for depression

16.3.24 In diagnosing depression, the current National Institute for Health and Care excellence (NICE) guidance requires at least one of a number of core symptoms along with three or four depressive symptoms. The core symptoms are; -Persistent sadness or low mood nearly every day; - Loss of interest or pleasure in most activities. The depressive symptoms are; -Fatigue or loss of energy; - Worthlessness, excessive or inappropriate guilt; -Recurrent thoughts of death, suicidal thoughts, or actual suicide attempt; - Diminished ability to think/concentrate or increased indecision; -Psychomotor agitation or retardation; -Insomnia/hypersomnia; -Changes in appetite and/or weight loss. Symptoms should have been present persistently for at least two weeks and must have caused clinically significant distress and impairment. They should not be due to a physical/organic factor (e.g., substance abuse) or illness (although illness and depression commonly co-exist). Severity is based on the extent of symptoms and their functional impact.[29]

16.3.25 On exploration with the GP, his depression was not formally assessed, nor is there a formal trigger to conduct an assessment and diagnosis of depression. On the one hand, it is arguable that during the summer of 2018, Samuel had a persistent low mood and several depressive symptoms such as weight loss that merited a more formal assessment or use of diagnostic tools to assess and monitor the severity of depression. Conversely, Samuel was seen by a number of GP's who knew him well and who saw him and Sarah regularly and were therefore able to monitor him, offering appropriate support. The use of these scales is not required for decisions about treatment and not only was he offered medication and counselling that he declined, but he was also appropriately signposted him to Carers in Herts and the Holistic Care team for further support and advice.

16.3.26 It is noteworthy that the detailed chronologies for Samuel and Sarah do not document any further concerns about stress or depression from October 2018 onwards and at no time did Samuel express any suicidal ideation.

[29] Source: Signs of Depression. Symptoms and Treatment - Patient | Patient (Accessed October 2020)

Samuel as Carer

16.3.27 On considering Samuel as a carer, it is clear from both his and Sarah's records that he had been identified as a carer in accordance with NICE guidelines (NG150)[30]. The practice has shown an awareness of social care involvement such as by; attempting to contact his social care case worker on 30th July 2018 and linking in with social care on 16th October regarding the burden of responsibility on him. More broadly, the practice has sought to support his 'carer needs' through signposting to Carers in Herts and engaging with the HoSF.

Summary Analysis in Respect of Keylines of Enquiry

Term 1: Information Sharing

16.3.28 Information sharing was proportionate, with information regularly shared across agencies such as referrals to secondary health care, HoSF and social care. However, apart from the MDT meetings, this was linear in nature with appropriate referrals being made and not more expansive across the system.

16.3.29 Examination of the chronologies identified two potential opportunities to strengthen information sharing within the practice. The first being with regard to where information is recorded in situations such as Sarah and Samuels, where information pertinent to Samuels low mood were recorded on Sarah's notes. As the review progressed, this learning opportunity has been shared with all practice staff (August 2021) and instruction given that all relevant information is documented in the relevant patient record when recording for spouses and partners.

> **(LO2) Learning Consideration/ Opportunity:** *Seek assurance that relevant medical concerns are documented on patient's personal records, when originally record on spouse's notes.*
>
> ***Response:*** *The GP practice has ensured that relevant medical notes are documented on patient's personal records, by sharing learning and giving instruction.*

16.3.30 The second relates to how observations from specialist nurses are flagged to GPs for consideration via the 'Patient Task' method as required. As above, this learning opportunity has been shared with all practice staff (August 2021), staff have been reminded and instruction given as to the use of the 'patient task system'.

> **(LO3) Learning Consideration/ Opportunity:** *Seek assurance that the patient task system is utilised appropriately:*
>
> ***Response:*** *The GP practice has ensured that staff have been reminded and instruction given regarding the use of the 'patient task system.*

Term 2: Key line of Enquiry 2-Assessment and diagnosis

16.3.31 Sarah and Samuel were both elderly and he had a number of medical issues to contend with in addition to caring responsibilities for her. It is apparent that he suffered from low mood and stress, particularly evident in the summer of 2018. On balance it seems, his concerns related to his caring responsibilities as opposed to worrying about his own health.

16.3.32 The GP practice provided a flexible response according to the needs of Sarah, seeing her frequently at the practice, but also at home when required or when she was unable to attend. Referrals were made to secondary health care specialists in relation to her suspected dementia and other agencies that included the TIA clinic, holistic care team and also the care

[30] Source: Recommendations | Supporting adult carers | Guidance | NICE (Accessed May 2021)

of the elderly team. They have also engaged with other agencies such as the HoSF on a regular basis as well as taking part in monthly MDT meetings.

16.3.33 The practice has identified him as a carer within the chronology in accordance with NICE guidelines and shown its awareness of social care involvement, Samuel already having been referred by EMDASS for a carers assessment in January 2018. It has also sought to signpost Samuel for support such as through Carer in Herts, as well as through engagement with other agencies noted above.

16.3.34 Samuel was clearly suffering from a period of low mood, and stress was considered a potential issue. Medication and counselling were offered and declined. Whilst no formal assessment was carried out, monitoring took place through frequent contact. Following a period during the summer of 2018, when these issues were apparent, these concerns diminished.

16.3.35 Whilst the challenges of safeguarding those with dementia are subject to a number of academic reports, no concerns were evident in Sarah and Samuels case. They were seen by a number of professionals including specialist nurses, and at least four different GPs in the practice and at their home.

16.3.36 There were no signs of domestic abuse to these professionals, though a potential barrier to the identification of domestic abuse includes the fact they were not asked about personal safety, in other words 'routine enquiry'. In discussion with the panel representative and GP, routine enquiry for all patients was deemed disproportionate, though it was felt the studies and links between mental health and domestic abuse provided an opportunity to consider more focused routine enquiry.

16.3.37 As above this learning opportunity has been shared with all practice staff (August 2021), staff have been made aware and instructed to make routine enquiry about domestic abuse when dealing with families living with dementia. In addition, this has been and continues to be reinforced at practice meetings. The practice is also exploring how this may be audited via its electronic patient recording system.

(LO4) Learning Consideration/ Opportunity: *Consider the merits of routine enquiry when dealing with patients living with dementia / mental illness.*
Response: *The GP practice has given instruction and continues to reinforce the need for routine enquiry when dealing with families living with dementia and is currently exploring how this may be audited via its electronic patient recording system.*

16.3.38 The GP reflected upon Samuel's reluctance to accept help, as having merited further exploration (16.3.19). In itself, this reluctance could be argued as a barrier to support, though clearly individuals have the right to be independent, even though this means they may struggle. The subject of professional curiosity has been the subject of Learning Bulletins shared with GPs in October 2020, with further work planned for 2021.

(LO5) Learning Consideration/ Opportunity: *Professional Curiosity- Reinforce the need for an open mind and, where necessary, an investigative mindset when dealing with patients who are reluctant to accept support.*
Response: *The subject of Professional Curiosity has subsequently been subject to and continues to be subject to Learning Bulletins that supports annual training programme.*

Term 3: Key line of Enquiry 3-Contact and Support

16.3.39 Sarah and Samuel were well known to the practice, benefitting from significant and accessible contact at the local practice and at their home address. The practice also engaged with their daughter 'Ann' being responsive to her concerns during consultations or when she phoned the practice, responding to her concerns in a timely fashion.

16.3.40 The GP had taken part in monthly MDT meetings, that were collaborative meetings involving the HosF and community matrons. The panel learned that these MDT meetings now only take place between the GP and HoSF. It is known that at there was over a period of months, ten agencies were involved at the same time with Sarah and Samuel. It therefore seems that the loss of, as opposed to expansion of, a wider forum to exchange information diminishes the opportunity to collaborate and co-ordinate across the system for the benefit of patients and family.

16.3.41 More broadly, the panel explored whether GPs would call professionals meetings or attend them if they were called, and it was explained that the practice would call and/or participate in professional's meetings, but in this case was assured that appropriate support was in place.

16.4 West Hertfordshire Hospitals NHS Trust (WHHNT)

Sarah

16.4.1 The WHHNT trust may be broken down into four main periods of contact. The first relates to routine attendance when Sarah appeared relatively healthy, a second period relating to treatment following admission via A and E, and a third period six months later when see by an elderly care consultant. The final period relates to Samuel and his attendance regarding ongoing medical issues. The latter three periods will be subject of focus herein.

16.4.2 Upon admission following a fall, a comprehensive history was taken from Sarah, and it was also noted that her husband and daughter were involved in contributing to the information picture for Sarah. Whilst this is good practice and her history of previous falls was noted, there was no apparent exploration or screening in respect of domestic abuse or safety at home. This Trust's approach to domestic abuse is explored below at 16.4.16.

16.4.3 Their daughter described how there had been a decline in Sarah's cognition and that the notes recorded Sarah lacked capacity and a decision was recorded Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR). However, there is no record of a capacity assessment or best interest decisions having been undertaken. NICE guidelines state "In line with the Mental Capacity Act 2005, practitioners must conduct a capacity assessment, and a decision must be made and recorded that a person lacks capacity to make the decision in question, before a best interest's decision can be made. Except in emergency situations, this assessment must be recorded before the best interest's decision is made" [31] This point has been subject of an individual agency recommendation,"

- *Medical staff need to complete Mental Capacity Assessments and best interest decisions when making decisions on behalf of others that lack capacity*".

16.4.4 Details were recorded about the level of help that Sarah required at home, in her day to day living that one may consider contradictory. On the one hand, Samuel described that Sarah was relatively independent in respect of washing, dressing, feeding herself and had good mobility. On the other hand, on transfer from the emergency department to a ward, Sarah's daughter described the level of support that Samuel provided to a physiotherapist who then recorded that Samuel was at risk of 'carers burden' This contradictory picture was not explored further at the time and the IMR author notes that improved professional curiosity may have given a greater insight into the overall social situation. This is subject to an individual agency recommendation.

[31] Source: https://www.nice.org.uk/guidance/ng108/chapter/Recommendations (Accessed June 2020)

- *The safeguarding team will continue to highlight the need for professional curiosity.*

16.4.5 Considering the impact on carers more broadly, the Alzheimer's Society suggest that six out of ten carers had been pushed to breaking point in the UK.[32] In WHHNT's response to Sarah and Samuel, a section 2 referral was made to Adult Social Care in respect of Sarah, though having identified Samuel as a carer in accordance with current NICE guidelines in respect of "Actively seek to identify carers"[33], he was not signposted for a carer's assessment.

16.4.6 The third period of engagement with Sarah occurred approximately six months later, when she was seen by elderly care consultant accompanied by Samuel and Ann. At this meeting it was reported that Sarah was still having falls at night and that this had been ongoing for about a year. Changes in medication were advised as were ant-embolism stockings. Further tests of night-time ECG and blood pressure monitoring were advised but were not subsequently reported back to the hospital.

16.4.7 During this period of engagement, the IMR author highlights the contradictory picture presented by Samuel and by his daughter. On the one hand Samuel says he is coping, and it is documented that Sarah dresses and feeds herself, has good mobility and therefore there is no requirement for a package of care. On the other hand, their daughter describes her mother's cognition as declining and the level of care her father is providing is growing and having an increasing effect on his wellbeing. The IMR summarises "There is no real insight into Samuels real social situation which could suggest a lack of professional curiosity. Samuels needs could have been further explored considering he too is elderly, having interrupted sleep and is the sole carer for his wife with dementia and recurrent urinary tract infections which result in incontinence. Carers UK, (2014) recognise that caring for an older or disabled loved one can take a serious toll on carers' mental and physical health, their personal relationships and without the support they need, this can lead to carers' collapsing through exhaustion, suffering physical injury, or becoming overwhelmed by stress and anxiety. A local recommendation has been made in respect of these observations.

- *The safeguarding team will continue to highlight the need for professional curiosity.*

Samuel

16.4.8 Samuel was a frequent visitor to the hospital regarding the routine screening of his prostate cancer. He was also seen in relation to gastric problems, light headiness, potential lung cancer and a hernia.

16.4.9 Whilst one may argue that these physical issues are not relevant to the review, it is contended that the breadth and volume of conditions demonstrate and add weight in showing the considerable stress that Samuel was under as a full-time carer for his wife whose own health was rapidly declining.

16.4.10 The IMR author highlights that In March, when being seen in relation to gastric problem, Samuel said he had low mood and was under stress. Whilst one cannot argue stress as a definitive cause of gastric problems, there is broad recognition of a link. The Canadian Society of Intestinal research notes "Many studies show that stressful life events are associated with

[32] Source: file:///C:/Users/mark-/AppData/Local/Packages/Microsoft.MicrosoftEdge_8wekyb3d8bbwe/TempState/Downloads/carers-at-breaking-point%20(1).pdf (Accessed May 2020)

[33] Source: https://www.nice.org.uk/guidance/ng150/chapter/Recommendations#identifying-carers (Accessed June 2020)

the onset of symptoms, or worsening of symptoms, in several digestive conditions, including inflammatory bowel disease (IBD), irritable bowel syndrome (IBS), gastroesophageal reflux disease (GERD), and peptic ulcer disease."[34] In Samuel's case, the medical notes do not report the causes of low mood or stress, neither do they report that he was asked. It may be that this was a missed opportunity to explore causation and appropriately signpost for other support in a holistic manner.

16.4.11 Whilst in one regard, stress may be argued as causational or an aggravating factor for physical ailments such as gastritis, it may be also argued that worries over one's own health may also add to or cause stress. The National Library of Medicine reports "A diagnosis of cancer is a very stressful event for the patients and their families. Patients, partners, and other family members can suffer from clinical levels of depression and severe levels of anxiety and stress reactions."[35]

16.4.12 The IMR author further suggests that the symptoms that Samuel was experiencing may have been the result of stress from caring for his wife, though he did not disclose that he was stressed or that he was a carer for his wife. The IMR author noted that it is documented that supporting a person suffering from dementia is stressful, and this is reflected by the Alzheimer's Society who reported in 2018, that 'nine in ten carers for people with dementia experience feelings of stress or anxiety several times a week – and a further 80 per cent find it difficult to talk about the emotional impact of caring'.[36] In addition to caring for his wife Samuel was experiencing a number of health issues of his own which he may not have been able to discuss with this wife due to her advancing dementia. It may be speculated that this led to feelings of isolation and helplessness.

16.4.13 Helpfully, it was noted that one reason people do not recognise themselves as carers relates to the nature of the caring relationship. Smyth (2010) suggests "When providing care for a family member, intra-familial bonds of love and reciprocity do not encourage parties to view the relationship as anything other than a 'normal' familial relationship".[37] In other words this may in itself be a barrier to recognising the need for assistance and that if this is recognised, this may assist agencies how to encourage carers to accept support without encroaching on their rights to make their own decisions.

16.4.14 What is clear from the WHHNT IMR and chronology, is that it was known that Samuel was under stress and also disclosed his low mood. His GP wrote to the hospital and said that he was likely to become extremely anxious if an operation to deal with his hernia had to take place and there were complications. Conditions he suffered from, may have been linked to stress and would have added to stress levels. And yet as the IMR author reports there was an opportunity to discuss his low mood and stress that did not happen or was not documented. Such broader holistic screening of Samuels social situation that may have enabled signposting or support to alleviate.

16.4.15 Moreover the IMR author has referenced a 'think family'[38] approach, noting there being limited information within Samuel's medical notes and yet when cross referenced with his wife's

[34] Source: https://badgut.org/information-centre/a-z-digestive-topics/stress-and-your-gut/ (Accessed June 2020)
[35] Source: https://pubmed.ncbi.nlm.nih.gov/15295777/ (Accessed June 2020)
[36] Source: Carers for people with dementia struggling in silence | Alzheimer's Society (alzheimers.org.uk) (Accessed April 2021)
[37] Source: Search results | Taylor & Francis Online (tandfonline.com) (Accessed June 2020)
[38] 'Think Family' Think Family means securing better outcomes for adults, children, and families by coordinating the support and delivery of services from all organisations. Neither adults or children exist in isolation and Think Family aims to promote the importance of a whole-family approach: https://www.derbyshiresab.org.uk/professionals/think-family.aspx#:~:text=Think%20Family%20means%20securing%20better,of%20a%20whole%2Dfamily%20approach.

notes, it is possible to establish a clearer picture of the additional stress he was under from caring with for his wife as this is well documented in her notes. Local recommendations reflect these observations.

- *All Trust staff should be aware of services within the Trust and externally to recognise and support patients who may be carers.*
- *The safeguarding team at West Herts Hospital Trust provide safeguarding training to all staff. Safeguarding level 3 has commenced for senior staff nurses and medical staff Professional. This is face to face training and includes safeguarding supervision. In these sessions there is a focus on encouraging professional curiosity, considering the importance of contextualised safeguarding and a 'think family' approach."*

Organisational Approach to Domestic Abuse

16.4.16 In practical terms the panel learned that routine enquiry regarding domestic abuse is used in the maternity setting, but not the emergency department or other settings. It was acknowledged there had been studies such as to the benefits of routine enquiry such as the Cochrane Report that found a two-fold increase in identification of domestic abuse, but also found that there was no increased uptake in accessing specialist provision, concluding there was insufficient evidence to justify implementation of IPV screening for all women in healthcare settings. Balanced against the merits of routine enquiry, the panel also learned that the IDVA service is co-located across the two hospital trusts serving the local area and that this had resulted in an increased referral rate to advocacy services. This is recognised as good practice.

Summary Analysis in Respect of Keylines of Enquiry

Term 1: Information Sharing

16.4.17 The trust recognised Sarah as vulnerable and submitted a safeguarding alert regarding her, as someone who may have care and support needs.[39]

16.4.18 The trust has also recognised a missed opportunity to explore contradictory information presented by Samuel and their daughter.

(LO6) Learning Consideration/ Opportunity: *Professional Curiosity- Reinforce the need for an open mind and, where necessary, an investigative mindset when presented with contradictory information.*
Individual agency recommendation refers: *The safeguarding team will continue to highlight the need for professional curiosity*

16.4.19 The GP alerted the trust as to Samuel's likely anxiety if he were to undergo a medical procedure.

Term 2: Key line of Enquiry 2-Assessment and diagnosis

16.4.20 The trust has identified that Sarah's mental capacity was not assessed and recorded best interest decisions in respect of DNCAPR, though Samuel and their daughter were involved in the discussions regarding this.

(LO7) Learning Consideration/ Opportunity: Mental Capacity – *To seek assurance that Mental Capacity is tested, and best interest's decisions are recorded.*

[39] Source: Eligibility criteria under the Care Act 2014 | SCIE (Accessed September 2021)

Individual agency recommendation refers: *Medical staff need to complete Mental Capacity Assessments and best interest decisions when making decisions on behalf of others that lack capacity.*

16.4.21 Staff dealing with Sarah had clearly identified Samuel as being at risk of carers burden and he does not appear to have been signposted for a carer's assessment. Also, when Samuel attended the hospital separately there was clear recognition that he was under stress and that an opportunity to explore causation and signpost was either not done or documented.

(LO8) Learning Consideration/ Opportunity: Safeguarding (Carer Assessment) - *To seek assurance that upon identification of carer needs, information is provided as to how to access a carers assessment.*
Individual agency recommendations refer:
a) all Trust staff should be aware of services within the Trust and externally to recognise and support patients who may be carers
b) "The safeguarding team at West Herts Hospital Trust provide safeguarding training to all staff. Safeguarding level 3 has commenced for senior staff nurses and medical staff Professional. This is face to face training and includes safeguarding supervision. In these sessions there is a focus on encouraging professional curiosity, considering the importance of contextualised safeguarding and a 'think family' approach."

16.4.22 Whilst not exploring his stress could in effect be a barrier to receiving support, it is also possible that a care giver not recognising themselves as a carer may also be a barrier to accessing support (16.4.13). The Trust has made individual agency recommendations in respect of recognising and supporting carers as well as provision of safeguarding training.

(LO9) Learning Consideration/Opportunity: Encouraging family members to recognise themselves as carers and accept assistance.
Individual agency recommendations above refer:

16.4.23 Whilst, the Trust recognised Sarah as vulnerable and submitted a section 2 alert regarding her, the trust recognised Samuels needs as a carer, but did not signpost him for a carers assessment. However, they have made a broad single agency recommendation regarding recognition and supporting carers as well as provision of safeguarding training.

16.4.24 WHHNT has recognised the missed opportunity to explore contradictory information presented by Samuel and their daughter, making a single agency recommendation in respect of professional curiosity (16.4.4).

(LO6) refers.

16.4.25 The issue of domestic abuse was not explored with Sarah and Samuel in A & E, though routine screening does take place in maternity units and there are specialist IDVAs based at the hospital. This is recognised as good practice.

Term 3: Key line of Enquiry 3-Contact and Support from agencies

16.4.26 There is evidence of holistic care discussions, with Samuel and his daughter included in the decision making around DNACPR and discussion with both next of kin and daughter around care and support required at home.

16.4.27 There was early recognition of the need for a social assessment and documented request was sent for this promptly in A & E.

16.5 Carers in Herts

16.5.1 Carers in Hertfordshire is a local charity, and its primary role is to advise and support unpaid carers - people looking after someone who is elderly, disabled, has a physical or mental illness or who misuses drugs or alcohol. There are two elements to the service, the first is a care planning service that is telephone based and the second part being ANC who provide specialist dementia nurses to support families who are in crisis in their caring role.

16.5.2 During the relevant period, there was limited initial contact via phone with Samuel in January 2018 following initial referral from his daughter and GP. Further phone calls in February and March took place, checking on Samuels needs as well as advising him of the services offered by CinH. Samuel declined assistance and in the absence of further information, this response is considered proportionate, listening to the wishes of the carer being in accordance with safeguarding principles.

16.5.3 After this initial period, further contact was not made until August when a team leader spoke to Samuel. Thereafter, CinH had four (4) telephone conversations and conducted one home visit to Sarah and Samuel. They also had two telephone conversations with their son, and one with their daughter and around six (6) contacts with other agencies all through to November 2018. At this point there was no further contact until the 2nd July, a further call with Samuel.

Sarah and Samuel

16.5.4 In their dealings with Samuel and the family, it wasn't until August that Samuel agreed to any help. An initial insight is provided from the summary of a telephone assessment *"When asked about support carer said: currently there is no support in place. Wife is in denial about condition and therefore it is very hard to obtain any support as she gets very angry when dementia is mentioned. When talking about his health carer said: his physical health is not good although he is coping well with looking after his wife, however, he does need some respite. When asked about how he is coping the carer expressed how he finds the dementia upsetting and challenging. His wife is in denial about it, and he cannot mention dementia in front of her. She follows him around the house, and he cannot have a telephone conversation without her being there. None of the family mention dementia in her presence and he is very wary about doing so. Therefore, it makes it extremely difficult to put in any support as they do not openly talk about it. When asked about his quality of life the carer said: he doesn't have a good quality of life at the moment as he is being dictated to by his wife's illness and her being in denial. He is so concerned about upsetting her that it would appear he would rather do everything himself rather than make her uncomfortable."*

16.5.5 This care planning discussion resulted in comprehensive range of actions being undertaken with the consent of Samuel. These included a referral being made to Hertswise, providing details of a local dementia hub, a referral being made to Crossroads *(Provides support for unpaid family carers and the people they care for in Hertfordshire)* and also to the ANC *(Nurses with experience in dementia care who work collaboratively with families and with other dementia care providers, sharing their expertise and giving them the support and skills needed.)*

16.5.6 In discussion with the panel representative, it was also noted that Samuel had been offered and declined free carers breaks.

16.5.7 Further insight into the situation is provided from the only visit undertaken by ANC. It was observed that Sarah found it difficult accepting that she had dementia and became angry when this was mentioned. This was described as her being in denial and resulted in Samuel not being able to talk about the diagnosis, the impact on family life and how to manage care needs appropriately. This was exacerbated by the fact that Sarah continuously followed Samuel around the house, a behaviour with a number of potential explanations that includes: having

unmet needs, not remembering where they are, feeling insecure and anxious. The effect on Samuel was that he had no space to talk. In the one visit, the nurse found it very difficult to speak to Samuel, even though Sarah was having her hair done in another room as he kept checking where she was, whether she was following him and listening. However, the ANC did manage to explore with Samuel that sometimes in his situation the person with dementia could become aggressive or excessively demanding. Samuel was clear that was not his situation but conceded that she did become irritable with him. On further discourse, one explanation may be that he was allowing her to dictate what was said and done, to avoid distress to her and an entry on the chronology (15/08/2018) supports this notion when he said 'she gets very angry when dementia is mentioned'. This visit resulted in Samuel saying that he had enough support in place and no further support was required. Putting oneself in Sarah and Samuels position, it may be argued that any reluctance to accept diagnosis of dementia and on his part the inability to talk about dementia in themselves were barriers to accepting and seeking support. Certainly, the IMR author notes this possibility "His caring role caused many difficulties for him as his wife was in denial of her diagnosis and thus refusing any supportive services input."

16.5.8 The IMR reports "Husband reported that prior to her diagnosis, Sarah was placid and easy going", though her subsequent behaviour may be summarised as 'challenging and difficult'.

16.5.9 In order to try and understand the changes in behaviour, the panel's attention was drawn to a variety of information sources. The Alzheimer's Society (AS) describes 'challenging behaviour as 'behaviours that challenge' emphasising that the person is not being deliberately difficult, and that the behaviour can be just as challenging for them as for the carer. [40] Accepting that Sarah's behaviour was changing, sources including the AS and others that describe the behaviours that manifest themselves, including; repeating the same question and activity over and over again; restlessness; night-time waking and following a partner or spouse around everywhere.[41] However effects may also include frustration and irritation that may 'escalate to the point where they express this through verbal or physical aggression'.[42]

16.5.10 The panel acknowledged that there are issues of domestic abuse from carer to the dementia sufferer and vice versa that professionals must remain alert to, though there is no evidence of a trail of abuse in the relationship between Sarah and Samuel. An American study in 2010 found that various characteristics of both the caregiver and care recipient can contribute to abusive behaviour, including; the caregiver's anxiety, depressive symptoms, social contacts, perceived burden, emotional status, and role limitations due to emotional problems; and the care recipient's functional capacity, severity and stage of the dementia, their aggressive and physical assault behaviours, depressive symptoms, and their social contacts.[43]

Policy and Training

16.5.11 The question of identifying domestic abuse within the two elements of CinH service, care planning service and ANC. The care planning service use a care planning tool template to assist with the conversation, and whilst not overtly asking about domestic abuse, it does specifically ask questions with regard to relationships with regard to the cared for, carer and others. Moreover, it also prompts conversation about 'choice and control'.

[40] Source: https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/behaviour-changes#content-start (Accessed October 2020)

[41] Source: https://www.nhs.uk/conditions/dementia/behaviour/ (Accessed June 2020)

[42] Source: https://dementiainformation.stir.ac.uk/home/changes-in-behaviour/ (Accessed June 2020)

[43] Source: https://dementia.stir.ac.uk/blogs/dementia-centred/2016-09-15/elder-abuse-and-dementia (Accessed June 2020)

16.5.12 ANC use a needs assessment as a conversational tool, that has a specific section on risk that included prompts on physical and mental health of clients, along with generic comments on relationships. As the review progressed, this needs assessment was due for review and the panel representative agreed that the risk section would be adapted to include a prompt on domestic abuse, that went live on the 26th August 2021.

16.5.13 The panel were reassured that Carers in Hertfordshire have regular domestic abuse awareness training provided in house. The subject is incorporated into annual safeguarding training that is compulsory, including DA training and relevant DA case studies for all nurses, advice workers and managers.

16.5.14 Their nursing staff are registered nurses who receive specialist training regarding dementia and who also receive monthly professional development. CinH have subsequently reviewed which staff ought to receive mandatory training and domestic abuse features in annual safeguarding training that is compulsory for all staff and volunteers.

16.5.15 During the review period, panel deliberations also informed the revision of the CinH Safeguarding Policy that included the UK government definition of domestic abuse to fully incorporate 'coercion and control' and was thereby reassured that the full scope of domestic abuse is presented and understood.

16.5.16 The panel also learned that CinH has a J9[44] domestic abuse champion who is also able to signpost and support carers on the issue of domestic abuse. J9 champions are provided with a half days training developed by domestic abuse charity Safer Places.[45]

16.5.17 Notwithstanding the commentary above, there were no clear signs of domestic abuse to CinH.

Communication with Carer

16.5.18 It is clear that Samuel became confused as to the number of agencies who were involved. On the 10th September 2018, it was noted "Carer getting confused with all the different services that call him. He has not heard from the dementia nurses despite me putting a verbal referral through on 15/8. Also not heard from Crossroads" and "Dad expressed that he gets confused with all the people that call him, which is totally understandable". This in turn raises an issue of how agencies were together collectively explored below. This confusion appears to have been acknowledged by Adult care Services, when on the 12th October they asked that ANC do not contact Samuel until a meeting had taken place across agencies. This had been scheduled for the 18th October. Ultimately ACN could not attend this meeting and there was no further proactive engagement with Samuel, or the family and the case was closed to ANC at the request of ACS.

16.5.19 Whilst the case was closed to ANC, CinH maintained contact with Samuel, with a follow up call in January when he declined any assistance, preferring to wait for the possibility of getting care at the hospice. They also had a conversation with their daughter who expressed concern for Samuel saying that he had lost 2 stones in weight and was struggling to cope and was depressed. Upon exploration with CinH, it was reported that the focus was on getting support in to relieve stress, as opposed to forming a medical diagnosis. One may argue that rapid weight loss could be seen as a signal of deterioration that merited an alert to social care and/or

[44] J9: The J9 Domestic Abuse Initiative aims to raise awareness of domestic abuse and assist survivors to access support safely by training professionals and members of the community to recognise domestic abuse and respond to survivors. Once J9 trained, the J9 logo is displayed, letting survivors know that they have a safe place to access information and use a telephone to contact support services. Source: https://www.saferplaces.co.uk/j9-initiative

[45] Source: https://www.hertssunflower.org/media/documents/sunflower-j9-leaflet.pdf (Accessed August 2020)

signposting for a carers assessment. The IMR has made an individual agency recommendation in relation to this,

- *A more regular yearly safeguarding refresher is being planned in order to incorporate it within our annual overall in-house Training and Development programme.*

Working with others

16.5.20 Whilst CinH worked primarily with Samuel, they did engage with Sarah and Samuels children, receiving calls and emails. It appears that there were potentially different and competing views as to the situation, those of Samuel and his children. On the one hand Samuel, doing his best to manage for the caring responsibilities and declining assistance, those of the children trying to secure help and the son described Sarah as not accepting her diagnosis and the effect on Samuel (18th August 2018) and the daughter who described Samuel as tearful, stressed and not coping (2nd January 2019). Upon exploration with CinH, this is not unusual, a carer putting the needs of his wife first whilst the children were worried about their father and wanted him to take greater care of himself. It may also show the difficulty families have in understanding the condition from the dementia patient's point of view, presuming the patient understand the effect of their behaviour, when actually they may not.

16.5.21 However, in this case, the communication with the family shows that CinH did engage with family members, but ultimately had to take the lead from the carer who declined assistance.

16.5.22 During these contacts, Samuel was signposted for support to other agencies, support networks as described at 16.5.5. This does show the breadth of the 'local offer' to patients with dementia and their carers.

16.5.23 CinH also engaged positively with a number of agencies, including the local Hospice and Adult Care Services to whom they made calls and received calls from in order to share information. They have also been proactive in following up where possible, such as following up with Crossroads care when Samuel had not heard from them. This shows good working relationships and confidence to share information.

16.5.24 The chair explored the relationship between CinH and Crossroads as it appeared that their nursing offer was similar. It was learned that CinH would refer to Crossroads and this may also be reciprocated. In this case having referred the case to Crossroads, CinH re-engaged with Sarah and Samuel owing to a lack of contact. Putting oneself in Samuel's position, this is understandably confusing and indicates an opportunity to strengthen the co-ordination across CinH and Crossroads or provide a 'feedback loop' that confirms receipt of referral and action taken.

16.5.25 CinH, were also appraised by the hospice and ACS of an intention to hold a professionals meeting on the 18th October. In the communication between ACS and CinH, it was suggested that they do not engage further with the family until the outcome of the meeting. Whilst CinH could not attend, a discussion followed and CinH were appraised that whilst Sarah's condition was deteriorating, the hospice environment was not suitable for her. It was agreed in that discussion that there was no further role for ANC at that point and the case was closed to that part of CinH (not the telephone support by carer support advisors). Given the last contact with ANC, this is seen as being consistent with Samuel's wishes.

16.5.26 On considering how, CinH works with others, the IMR author identified a challenge in respect of the use of databases. They use data from three systems; (a) Charity log, is used to take referrals for the service from Alzheimer's, Age UK and HertsHelp and Data is shared across these three organisations. This does not include any clinical data but allows services to know who else is working with the client. This was in place at the time of the incident; (b) Wanda,

the current clinical database for ANC and the only place that full details of their work are held. This is only accessible to ANC and a senior manager in Carers in Hertfordshire. (c) Salesforce, the Carers in Hertfordshire database where all work completed by other staff in Carers in Hertfordshire is recorded. ANC currently only says when they open and close a case and which nurse is working with a family. The IMR author acknowledged that differences in use of databases was challenging and in Sarah's case, the practical effect was that he CinH community support advisor was unaware that ANC had made contact with Sarah and Samuel.

16.5.27 CinH has subsequently reviewed these systems of working and they will retire the Wanda database in the summer of 2021 and use Salesforce, ensuring better communication across CinH teams and ensure all clients are on a single database. This will minimise the risks of miscommunication for carers and clients by reducing the number of databases used from three to two. The panel recognise this as a useful development.

Summary Analysis in Respect of Keylines of Enquiry

Term 1: Information Sharing

16.5.28 CinH worked across a number of partner agencies such as Adult Care Services, the local Hospice and Crossroads care services. Whilst they were aware of an MDT meeting take place, they were unable to attend and there is evidence that the details were shared in a conversation between HoSF and CinH.

16.5.29 CinH identified that the use of different databases at the time, risked information not being available and missed, placing reliance on MDT meetings. Within CinH, this resulted in a community support advisor not being aware that ANC had been in contact. An internal review of systems of working will result in the reduction in the number of databases used from three to two in the summer of 2021, thereby improving internal communication.

16.5.30 CinH had referred Sarah and Samuel to Crossroads care, a partner organisation that provides nursing care. The fact that Samuel reported Crossroads had not been in contact, resulted in ANC nurses attending. This suggests an opportunity to improve communication and the feedback loop between the organisations.

> **(LO10) Learning Consideration/ Opportunity**: *To seek assurance that the systems of communication and information sharing are robust and enable effective and timely information sharing.*
> **Response:** *Carers in Hertfordshire have reviewed the implications of using different databases and will move to a single database for all casework records from Summer 2021.*

16.5.31 The agency sought to work with the carer and wider family, engaging with the son in particular to gain an overall view of circumstances.

Term 2: Key line of Enquiry 2-Assessment and diagnosis

16.5.32 CinH have engaged with family members via phone and email, in order to gain an understanding of need, they found Samuel putting her needs above his own, reluctant to accept support, portraying a contradictory picture to his children who were attempting to secure support, interpreting information differently.

16.5.33 As Sarah's dementia progressed, her behaviour became more challenging for Samuel. Whilst Samuel initially declined help, he did eventually accept some limited support. During the one visit, it was apparent that he was not at ease, constantly concerned about Sarah and whether she would overhear him taking about her dementia. Coupled with an observation that Samuel

was becoming 'overwhelmed' with the number of agencies involved, one may conclude that the overall situation was having an adverse effect on Samuel's wellbeing.

16.5.34 Given the indicators of increased stress, such as weight loss, it may be argued that an adult safeguarding alert could have been completed. A single agency recommendation has been made regarding this.

> **(LO11) Learning Consideration/ Opportunity**: *To recognise and respond to the signs of stress by a carer and consider safeguarding alerts.*
> **Individual Agency Recommendation refers.**
> *A more regular yearly safeguarding refresher is being planned in order to incorporate it within our annual overall in-house Training and Development programme.*

16.5.35 Whilst it was difficult for the agency to spend time with either Samuel or Sarah and a reluctance to talk about the diagnosis of dementia or provide an opportunity to talk freely about home circumstances and any issues of safety, there were no clear signs of domestic abuse.

16.5.36 On exploring the training of staff and ability to recognise and respond to signs of domestic abuse, the panel were reassured of mandatory safeguarding training that incorporated domestic abuse. Panel deliberations has also informed the revision of the CinH Safeguarding Policy and coverage of domestic abuse to fully incorporate 'coercion and control' has been added to internal training, that all staff complete annually.

16.5.37 The two elements of the service, care planning and ANC use a care planning tool and needs assessment respectively. The first prompts professionals to enquire about relationships and choice and control. The second needs assessment contains a risk section that CinH has agreed to adapt with effect from 26th August 2021

> **(LO12) Learning Consideration/ Opportunity:** *Seek assurance that local DA policy includes the government definition and definition of controlling and coercive behaviour, and that training reflects this broader definition.*
> **Response:** *Safeguarding Policy amended, and training incorporates all aspects of domestic abuse*
> ***Response**: ANC nurses risk assessment adapted to include a question/prompt on domestic abuse*

Term 3: Key line of Enquiry 3-Contact and Support from agencies

16.5.38 The agency had good lines of communication with partner agencies and telephone contact with Sarah's children.

16.5.39 There is evidence of collaboration with other agencies such as Adult Care Services, the local Hospice and Crossroads care services. They were also invited to an MDT meeting but were unable to attend.

16.5.40 It appears that the number of agencies working with Sarah and Samuel did become confusing, when in October 2018 Adult Care Services advised ANC not to make further contact, whilst CinH maintained telephone contact. CinH has subsequently reviewed these systems of working, ensuring better communication across CinH teams and ensure all clients are on a single database. This will minimise the risks of miscommunication for carers and clients. The panel recognise this as a useful development.

16.6 Hertfordshire Partnership University NHS Trust (Early Memory Diagnosis and Support service – EMDASS)

16.6.1 Sarah had undergone a cognitive assessment (ACE) in February 2019. As part of the EDMASS pathway, Sarah's details were passed onto the Alzheimer's Society to discuss post

diagnosis support. There was then a delay in post diagnosis support by EDMASS until June as Sarah was not deemed a priority and owing to a long waiting list.

16.6.2 This was explored with the provider who explained that patients may be given a priority if an urgent need is identified or if requested on referral. In Sarah's case an urgent need was not identified at the point of initial screening and a request was not made.

16.6.3 It was also explained that the pathway and recording was different at the time, with Alzheimer's Society more embedded within EMDASS and writing on EMDASS notes. Because of the pathway at the time, patients were in effect open to EMDASS and AS, staying open to EMDASS in case they needed any additional input. This caused some confusion when attempting to unpick the chronology.

16.6.4 The panel representative further explained that in the revised pathway, it was likely that a client would be discharged from EMDASS at the point of diagnosis, in other words once the diagnosis is complete, passed on to the Alzheimer's Society for ongoing support. The case would only be re-opened if a need for further 'support' were identified that EMDASS could provide. In Sarah's case, this would have been for the provision of telecare equipment. And once again, it would be expected that once the equipment had been provided, the case would be closed. This evolution in pathways now provides clarity as to what agencies are responsible for.

Risk Assessment

16.6.5 The memory nurses used two templated records to provide an overall assessment of need and then risk. The first is an initial assessment of overall social circumstances, that covers family history, forensic history, the persons strengths and support networks, health factors, medication, and mental health. The second risk assessment document covers; risk of self-harm; to self and others; self-neglect; abuse/ or neglect by others, abuse, and neglect. The form continues to record a history of risks, other concerns, and risk factors. This form does not ask any routine screening questions in respect of domestic abuse.

16.6.6 Whilst it is not suggested there was domestic abuse between the couple, the subject of the systemic invisibility of DA in the elderly is subject to commentary elsewhere within the overview report, as is the concept of routine screening. Furthermore, we know that Sarah's actual cognitive assessment was conducted alone, but it is less clear if the risk assessment was conducted alone as the specific section asking who was present was incomplete. Two opportunities arise, the first being the routine screening for domestic abuse and the second to ensure that risk assessments are conducted in private. The panel representative agrees these are reasonable assertions for HPFT.

16.6.7 The IMR author reports that as part of the routine risk assessment, they ask whether those they are involved with have access to weapons. In Sarah's case the notes state "none advised of in the home". This was clarified by the panel representative and the answer was 'No'. It was further clarified that this question relates to the safety of staff carrying out home visits. Had the answer been 'yes', this would have informed the overall risk assessment.

Assessment of Social Circumstances and Need

16.6.8 The initial assessment of social circumstances described that Samuel had taken over responsibility for finance and household tasks, that Sarah had experienced a gradual decline in her memory but was fully independent in self-care needs and went shopping with Samuel. The nurse recorded in the care plan that post diagnostic support was discussed and Sarah was given an information folder. Sarah agreed for her details to be passed onto the Alzheimer's Society for them to contact her by phone to see if she would like to receive further

post diagnostic support. Considering these factors in isolation, it is understandable that she was not deemed to be a high priority.

16.6.9 However, having been assessed on the 5th February 2018, but unknown to HPFT (EMDASS) or AS was that on the 6th February Sarah's daughter expressed concern her father was struggling to cope. This was known to the GP and social services. This apparent conundrum poses a number of challenges including; **(a)** the extent to which a carer is being candid, owing to pride, not recognising their own need, disguised coping or wishing to maintain control of circumstances and how professionals' probe to find out; **(b)** the extent to which agencies share information and concerns and with whom.

16.6.10 Mindful of the counsel of perfection that is hindsight bias, it may be argued that in addressing **(a)** the extent to which a carer is being candid, there is a need for professionals to be alert to the possibility that clients and carers may not share all concerns for a variety of reasons, requiring improved professional curiosity.

16.6.11 In addressing the point above **(b)** the extent to which agencies share information, this information was known to another agency, and it would not be reasonable to expect HPFT to seek such information. It is also debatable as to whether a professional such as the GP on receiving such information, knowing that their patient is being seen by a specialist service would consider passing it on, as it did not directly relate to the clinical treatment of Sarah.

Timeliness and Post Diagnosis Support

16.6.12 The four month time period between initial assessment and contact by a dementia support worker (4th June 2018) meant that there was a delay in offering to pass Samuel's details on for a carer's assessment. On this first contact, he consented to his details being passed to adult social care. The IMR author notes that the delay in engagement between ACS and the family may have caused extra strain for Samuel.

16.6.13 Whilst there was a delay in support owing to the waiting list, it was provided for within the 38-week period time limit from the point of referral. EMDASS occupational health offered a home visit that was declined and thus relied on telephone contact. Samuel was sent information packs and signposted and supported to a breadth of relevant community organisations, support groups and advised of relevant welfare benefits. It was also during this consultation that he declined a Cognitive Stimulation Therapy Group for Sarah. This is subject to discourse below.

16.6.14 Further considering issues of carer burden, one article on caregiver burden reports, 'The demands and negative impacts of dementia caregiving are generally higher than nondementia caregiving' and that 'they also report greater employment complications, caregiver strain, mental and physical health problems, reduced time for leisure and other family members, and family conflict.'[46] Since risk and social need are not necessarily static it is likely that any such strains may build over time and that one means of identifying changes in social circumstances would be for more frequent 'check ins' to take place.

16.6.15 The notion of 'check ins' was discussed with the panel representative and owing to the clarity provided at 16.6.3 as to discharging cases post diagnosis, it is agreed that the ongoing support is now clearer and would be provided by the Alzheimer's Society.

16.6.16 Thereafter, an EMDASS occupational therapist made contact to discuss Telecare equipment and Samuel declined a home visit and details were sent by post. Two further calls were made (24/8) and (25/9), by way of follow up and no additional support needs were identified, and

[46] Source: Caregiver Burden - an overview | ScienceDirect Topics (Accessed November 2020)

Samuel described having a very supportive daughter (family). The EMDASS pathway was re-explained, and consent confirmed for the case to be handed on to Alzheimer's Society community dementia support team. EMDASS concluded this with letters and information being sent to Sarah. Given these conversations this decision was understandable.

The Voice of Sarah

16.6.18 It was noted that Sarah's cognitive assessment was conducted without Samuel being present. This is one of the few occasions when she was seen alone in her dealings with agencies. The reason for seeing her alone is to avoid anyone prompting answers to questions during an assessment. Relatives only attend these assessments if a patient is agitated, and Sarah was not.

16.6.19 Thereafter contact between the dementia support worker appears to have been solely with Samuel, on the basis of a decline in Sarah's cognitive ability, her recorded wish not to talk about her dementia and Samuel having had power of attorney for health and welfare decisions.

16.6.20 This poses a challenge, in that her stated wish not to talk about dementia and/or the deterioration in cognitive function meant that she no longer had the capacity to understand what was happening, could be interpreted as disempowering her. As the IMR author points out, the NICE Dementia guideline NG97 of 2018 states; "All people and their carers with a new diagnosis of dementia should be offered post diagnostic support written information relevant to their condition and an opportunity to plan for their future." Additionally, the principle of empowerment described by NICE guidelines says, "Encourage and enable people living with dementia to give their own views and opinions about their care."[47] This same guidance also provides information as to ways of communicating with people living with dementia. In Sarah's case, Samuel declined cognitive stimulation therapy on her behalf[48] and it seems that this may have been a therapy with the potential to help, and yet the extent to which she was made aware of this therapy is unknown as is the decision to decline it.

16.6.21 Linked to this theme is the matter of the principles of the Care Act and in particular 'empowerment' and whether Sarah's view should have been more actively sought, and if not a documented rational as to why not.

16.6.22 It could be argued that if one does not, or has not sought her view, it could not be determined whether she was subject to a degree of control, whether that be inadvertent and well intentioned, or part of a pattern of wider control and coercion. Balanced against this is that Sarah had a loving husband of many decades who had power of attorney and had her best interests at heart. It is not suggested that he didn't', but it is arguable that the independent professional must in following the principles of empowerment, continuously test that notion through enhanced professional curiosity, testing mental capacity as required.

16.6.23 This raises a number of questions, including reliance upon Samuel and his description of the legal status, including; a) what proof would be expected to be provided regarding power of attorney and a view that she did not wish to discuss her diagnosis with others and b) the extent to which an agency actively seeks, ought to seek or is obliged to seek information on this point. Whilst the panel representative explained that the subject of power of attorney is subject to routine questioning, it was acknowledged that asking for evidence of its existence occurs less frequently.

[47] Source: https://www.nice.org.uk/guidance/ng97/chapter/Person-centred-care (Accessed June 2020)

[48] Cognitive stimulation therapy (CST) is a widely used, evidence-based intervention for people with dementia (PwD); Source: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4267515/ (Accessed June 2020)

16.6.24 The panel representative raised this with the safeguarding lead and EMDASS operational leads who agreed that the welcome literature requires updating, to include information about legal power of attorney for those who don't have it, and that they may be asked for a copy if it is stated a partner or family member has it.

The Voice of Samuel

16.6.25 Samuel was the single point of contact regarding Sarah. As noted above HPFT sought and gained his permission to pass details to ACS for a carers assessment. EDMASS has also signposted and offered a variety of other support measures that included, signposting for a blue badge, securing consent to share details with the Alzheimer's society, signposting to Hertswise.

16.6.26 Whilst records note him as managing in his caring role. Samuel was recorded as having cardiac investigations and feeling tired, exhausted, and stressed at times. This was considered by the panel and accepted as common emotions felt by carers in these types of circumstances. In seeking permission to pass details to ACS for a carers assessment, the benefits of such planning would have included how support could help alleviate stress and tiredness he felt. As such, it is reasonable to presume that the information and permission around a carers' assessment and engagement with ACS would suffice.

Collaboration and co-ordination

16.6.27 It was noted in the IMR submitted that post diagnosis support is transferred to a EMDASS Alzheimer's Society member of staff who hot desk at the Trust, but that HPFT had no line management responsibility for this team.

16.6.28 On exploring how cases were handed over from HPFT/EMDASS to the Alzheimer's, it was established that there were, and continue to be weekly multi-disciplinary team (MDT) meetings attended by the society's Dementia Support Manager. It was also learned that Dementia Support Workers attend EMDASS Post Diagnostic Support meetings with the HPFT memory nurses, OT's, psychologists, Speech and Language Therapist and Community co-ordinators.

16.6.29 The handover mechanism between HPFT and the Society in early 2019 was either by an EMDASS team member emailing the dementia support manager, and/or by details being offered to the dementia support manager during the regular MDT meetings. It has been suggested that a more formal referral process, possibly based upon the Alzheimer's Society national referral process, be adopted. This would involve HPFT completing a referral form with relevant data but to date this suggestion has not been taken up.

Training

16.6.30 The matters of discussion noted above prompted exploration of ongoing training with the panel representative. It was confirmed that all EMDASS staff complete Safeguarding Level 2, Level 3 and Mental Capacity Act training every three years that includes covering domestic abuse. Staff are also able to access material produced by the Hertfordshire Safeguarding Adults Board.

Summary Analysis in Respect of Keylines of Enquiry

Term 1: Information Sharing

16.6.31 Sarah's involvement with EMDASS followed a referral from her GP. Following initial assessment, she was not deemed a priority. Whilst her GP had subsequently learned that Samuel was feeing stressed, it is not considered reasonable for EMDASS to have known this,

nor indeed for the GP to have considered passing this information on to influence any prioritisation as, a request was not made, nor were his anxiety levels deemed serious enough to make such a request.

16.2.32 EMDASS and AS work closely together and it was explained that AS have access to EMDASS systems and information. Subsequent changes to pathways in effect result in clients being closed to EMDASS at the point of diagnosis and handed over to AS who use their own client care system (see 16.11.6). This now clarifies which agency now has responsibility for clients.

Term 2: Key line of Enquiry 2-Assessment and diagnosis

16.6.33 Sarah was assessed as being a low priority and Samuel did not request her being made a higher priority. Given that we know their daughter had spoken to the GP about how Samuel was struggling, this is seen as reminder to professionals to consider the possibility that clients may not be entirely candid with them.

16.6.34 There was no clear information about domestic abuse in the relationship between Sarah and Samuel, but nor was she asked. The concept of systemic invisibility for domestic abuse in the elderly has been subject of research and it is having been agreed by the agency through this review to address this issue by adapting the triage document to include questions on domestic abuse, ensuring that staff are able to recognise and respond to abuse.

> **(LO13) Learning Consideration/ Opportunity:** *Develop risk assessment protocols to ask routine screening questions on domestic abuse and ensure risk assessment takes place in private.*
> ***Recommendation 2:*** *HPFT-EMDASS to adapt their risk/needs assessment protocols to include a question/prompt on domestic abuse.*

16.6.35 There was a four-month delay in between initial assessment and further contact. The current and revised pathway now ensures that once 'active work' has been concluded, the case is closed to EMDASS and passed to the Alzheimer's Society. This evolution provides clarity as to what may be expected from EMDASS.

16.6.36 There was significant reliance upon Samuel who has legal power of attorney, and whilst on the one hand, Sarah indicated at the initial assessment she did not want to talk about dementia, her voice was absent in further engagement with EMDASS, and there is no evidence of her involvement in decision making. Arguably this is in accordance with NICE guidelines and the principles of the Care Act, as she did not want to talk about dementia, though it would be highly unlikely that she would be spoken to again given the system described at 16.6.32. Whilst the panel representative explained that the subject of power of attorney is subject to routine questioning, it was acknowledged that asking for evidence of its existence occurs less frequently.

> **(LO14) Learning Consideration/ Opportunity:** *Ensure that agencies satisfy themselves as to the existence of relevant legal power of attorney for their patients.*
> ***Recommendation 3:*** *HPFT (EMDASS) to require proof of legal power of attorney for patients.*

16.6.37 On considering the need for any further learning and recommendation on this point, the panel took into account; (a) the comprehensive training regime noted at 16.3.30 above, and (b) the revised pathway that ceases EMDASS involvement post diagnosis.

Term 3: Key line of Enquiry 3-Contact and Support from agencies

16.6.38 The ability for Alzheimer's Society to work within the same office space as EMDASS, to share information and access systems and information, to take part in MDT meetings is seen as

positive. The evolution and clarity as to roles and closures of cases to EMDASS and handover to AS is seen as a welcome development.

16.7 Hertfordshire Community NHS Trust

16.7.1 There was only limited contact, with Sarah referred to two services, Community Therapy, and the Bladder & Bowel Service. The referral to community therapy in late December 2017 followed a series of falls and this resulted in an initial home visit within two weeks by an occupational therapist. Recommendations were made in respect of equipment, but subsequently cancelled by Samuel as the equipment was sourced by the family. Contact with regard to community therapy and equipment was all concluded within six weeks.

16.7.2 As a matter of completeness, the trust has an up-to-date web page on domestic abuse.[49] Similarly it has an up-to-date web page in respect of safeguarding.[50]

Summary Analysis in Respect of Keylines of Enquiry

Term 1: Information Sharing

16.7.3 Information was received and triaged by each service via a referral system called SystemOne. There was no wider sharing of information, nor cause to consider sharing information.

Term 2: Key line of Enquiry 2-Assessment and diagnosis

16.7.4 During initial consultation by community therapy - occupational health, for equipment to help, Samuel explained that he did the household chores. The IMR author notes this may have been an opportunity consider discussing a carers assessment, though there were no clear indicators of a pressing need.

> **(LO15) Learning Consideration/ Opportunity:** *Seek assurance that staff are able to recognise the potential for carers to be referred for carers assessments.*
> ***Individual agency recommendation refers:*** *All staff to be aware of carer's needs and to offer a carer's assessment.*

16.7.5 The contact with Hertfordshire Community NHS Trust Bladder and Bowel service was limited, having received a letter Samuel contacted them, explaining that owing to a number of other appointments he would contact them in the future. A month later he explained to them that Sarah was under the care of another department and was buying pads privately, before returning to them nearly a year later.

16.7.6 None of the contacts provided an opportunity to consider the impacts of Sarah's health on Samuel, or whether there was any indication of domestic abuse or to barriers to seeking support.

Term 3: Key line of Enquiry 3-Contact and Support from agencies

16.7.7 There was insufficient volume and depth of contact, to indicate domestic abuse. There was no need to contact agencies, or to collaborate beyond the receipt of the referrals for the two services offered by the Trust. Similarly, no issues of intersectionality were apparent.

[49] Source: https://www.hct.nhs.uk/children-and-families/domestic-abuse/ (Accessed June 2020)
[50] Source; https://www.hct.nhs.uk/about-us/safeguarding/safeguarding-adults/ (Accessed June 2020)

16.8 Adult Care Services

16.8.1 Sarah and Samuel first came into contact with Adult Care Services (ACS) in January/February 2018 following a referral made by (WHHNT) regarding a request for handrails to support Sarah when accessing her home. Further contact did not take place until June when the volume of contact and communication increased, as did the apparent frustrations of Sarah's and Samuel's frustration with the system. The volume of contact and matters arising during this period are broken down into a number of themes in order to draw out the learning, starting with the perspective of Sarah and Samuel.

The Voice of the Client -Sarah

16.8.2 As a broad reflection on interactions reported in the chronology and the IMR, they do not speak to the voice of Sarah with the IMR stating "I can see no evidence of Sarah being seen without her husband or a conversation taking place to enable her to express her views." This is supported by examination of the chronology, where there are no entries where Sarah's voice is clear and present. Even at first contact it was reported that Samuel had said that he could not speak openly because his wife was standing next to him. This theme continued throughout ACS engagement with the family, with the voices and views of Samuel and their children being clearer.

16.8.3 This raises a number of matters, including; whether Sarah's capacity to comprehend and make decisions was understood and tested at the time and over the following months; working to safeguarding principles; the potentially isolating effect whether well intended or otherwise; whether Sarah's needs were properly assessed by ACS; whether there was domestic abuse and controlling/coercive behaviour in the relationship.

Capacity and Dementia

16.8.4 The five principles of the Mental Capacity Act include the first that says, 'A person must be assumed to have capacity unless it is established that he lacks capacity'. [51] The issue of Sarah's capacity does not appear to have been explored from the outset, with Samuel making decisions, such as when he declined the referral and assessment from WHHNT in respect of having rails fitted.

16.8.5 On considering the two-stage test in respect of capacity (a) whether there an impairment of, or disturbance in, the functioning of the person's mind or brain? and (b) if so, is the impairment or disturbance sufficient that the person lacks the capacity to make that decision; it is clear that Sarah suffered from dementia and therefore stage one of the tests would have been met. The second stage does not appear to have been considered with a subsequent reliance on Samuel and their children. Whilst this is true, the question of mental capacity and who makes those assessments is not clear cut. As described on the Social Care Institute of Excellence (SCIE) website, the person who makes the assessment is "the person who might have to do something in the person's best interests".[52] The same source goes onto to advise "Involve the person in the decision as much as possible: find out what their views and wishes are (including those they had before they lost capacity to make the decision) and where possible involve the person in all meetings where decisions are being made about them." [53] ACS have made a

[51] Source: https://www.legislation.gov.uk/ukpga/2005/9/section/1 (Accessed June 2020)
[52] Source: https://www.scie.org.uk/dementia/supporting-people-with-dementia/decisions/capacity.asp (Accessed June 2020)
[53] Source: https://www.scie.org.uk/dementia/supporting-people-with-dementia/decisions/best-interest.asp (Accessed June 2020)

single agency recommendation in addressing this learning opportunity and mandatory training regarding mental capacity and best interests' decisions.

- *Ensure staff members attend training in relation to Mental Capacity and Best Interest decisions.*

Safeguarding principles

16.8.6 Expanding the discussion further, to consider the 'Safeguarding Principles' as outlined in the Hertfordshire Safeguarding adults at risk -multi-agency policy, procedure, and practice for working with adults at risk of abuse or neglect[54], it may be argued that the approach to the first principle of 'empowerment' risked being undermined, as Sarah's view was not actively sought in ACS dealings with her. ACS have made a specific single agency recommendation in respect of safeguarding.

- *Staff to attend all Safeguarding training courses both face to face and on I-Learn as well as ongoing refresher courses.*

Isolation

16.8.7 Considering the overall circumstances through the lens of domestic abuse, one of the possible effects of not seeking Sarah's view or only speaking to Sarah with Samuel or others present may have been isolation. The IMR author notes that ACS workers were not able to assess Sarah alone and this poses the question as to the extent to which the Samuel was controlling contact and whether there were sufficient efforts to understand and then document reasons why she hadn't been seen alone. In other words, an opportunity to show improved professional curiosity.

16.8.8 However, from what we know and understand of their long marriage, friends described his love and how he doted on her. In the absence of any other information to triangulate concerns about control, it may be reasonable to deduce, that he was doing his best to care for her and prevent distress to her.

Record Keeping

16.8.9 The IMR author also notes that there is no record of the reasons as to why she hadn't been seen alone and along with other incidents of records not having been maintained (30th July) 2018 has made a single agency recommendation.

- *Improve recording on ACSIS, encourage staff to attend "Good Recording" training course already offered by ACS Learning and Development.*

Sarah's Needs

16.8.10 A further possible effects of not seeking Sarah's view was that she did not have all the relevant assessments completed that one would normally expect. The IMR author notes that ACS workers were unable to assess Sarah and did not complete a face to face 'connected lives assessment' that is a new local model for social care developed by ACS Care Services in Hertfordshire to shape work under the Care Act 2014. [55] This model was introduced in March 2018.

16.8.11 Upon exploration of the completion of assessments, it was learned that they are not automatically completed. A strengths-based practice emphasises people's right to self-determination, where skills and assets underpin working with clients. Described in a council

[54] Source: https://www.hertfordshire.gov.uk/media-library/documents/adult-social-services/herts-safeguarding-adults-board/hcs-666-issue-11.pdf (Accessed June 2020)

[55] Source: An Introduction to Connected Lives | Introduction (hertfordshire.gov.uk) (Accessed December 2020)

publication, it explains 'the approach gives a renewed emphasis on professional practice and accountability and will deliver a preventative and outcome focused approach to care planning. At the core of connected lives is a steadfast belief in social workers' and occupational therapist's professional judgment, values, and practice. Prescriptive assessments have been replaced with citizen and professionally led assessments that don't require management sign off'.[56] In this case, and with the counsel of perfection that is hindsight, the panel representative agrees such an assessment would have been useful, but also notes staff may not have completed it, as the family were making arrangements for a residential placement.

16.8.12 In discussion as to how the necessity and quality of 'connected lives assessments' and 'risk assessments' is overseen, the panel learned that since this review, there is a Connected Lives Board and also a Practice Management Board. These boards examine current practice and oversee monthly audits of assessments that also includes mental capacity assessments and best interest decisions. This auditing requires scrutiny on a monthly basis by management on their own teams, but also conducting peer reviews of other team assessments. The circumstances and learning of this review will be presented to these boards.

Domestic Abuse

16.8.13 Whilst there were no indicators of domestic abuse apparent to ACS, it is also apparent that Sarah was not asked, nor did ACS have the opportunity to ask her in private. There are a number of well documented reports, suggesting that domestic abuse is not sufficiently recognised in elderly populations. Safelives report suggests that there is systematic invisibility of domestic abuse and that 'This lack of recognition amongst some professionals is crucial given disclosure of abuse is more likely if victims are offered repeated opportunities to do so. This is particularly the case for older people who are less likely to access services through self-referral in the elderly population'. [57] This point of reflection by ACS had initially resulted in a single agency recommendation.

- *"Improve awareness of domestic abuse for staff. "*

16.8.14 Upon further discussion on routine enquiry about domestic abuse, ACS like other agencies agreed that it would be beneficial to adapt their risk/needs assessment protocols to include prompts on domestic abuse.

The Voice of Samuel

16.8.15 Samuel an elderly man was at the time managing his wife whose dementia was deteriorating as well as managing a number of his own ailments that he disclosed to ACS over time. From first contact, and throughout his engagement with ACS, it seemed that he found difficulty or couldn't speak in front of his wife. He also presented a contradictory picture to ACS professionals, informing them that he was coping and initially declining a carers assessment compared to his family describing him as struggling to cope, using the words "unhappy, depressed and lonely". When a carers assessment was completed on the 10th July 2018 in line with the Care Act, the CCO was able to have a discussion with Samuel alone, but he did not disclose that he was not coping. It was at this stage that Samuel relayed that his wife had savings above the ACS capital threshold of £23,250.00 and acknowledged that she would have to pay for any services. This became a point of contention for the family discussed below.

16.8.16 Also, putting oneself in Sarah and Samuels position, it was perhaps clear early on that they would find it difficult in managing the overall situation. In Jan 2018, the prospect of a first assessment for adaptations on the house was declined as Samuel said, Sarah was feeling overwhelmed by the number of assessments already undertaken by professionals. At this

[56] Source: connected-lives-a-model-for-social-care-in-hertfordshire.pdf (Accessed April 2021)

[57] Source: *Safe Later Lives - Older people and domestic abuse.pdf (safelives.org.uk) (Accessed December 2020)

stage they were only dealing with two agencies and one can only imagine how confusing the involvement of another eight agencies later in 2018 would become. However, Sarah and Samuel were supported by their children who advocated on their behalf.

The Voice of the Family

16.8.17 Sarah and Samuels children were interested in managing the care and actively advocating on their parent's behalf with ACS from the outset. Despite their daughter living abroad, ACS showed a desire and willingness to involve her through open lines of communication, be that telephone call, email, and face time. It is clear that ACS made significant efforts in this regard.

16.8.18 Notwithstanding these efforts, a number of clear frustrations expressed by the family are apparent from the chronology. These include; - financial implications and requirements to pay for care; - understanding and delays regarding a continued healthcare assessment; - securing respite for Samuel; - a seemingly slow process in getting practical help.

Financial Implications and Continued Healthcare Assessment

16.8.19 In July 2018, it became clear that Sarah and Samuel would be responsible for funding care, as they had savings over £23,250.

16.8.20 There were numerous exchanges between ACS and the children regarding the financial implications and the belief that their parents should be entitled to continuing healthcare provision. It seems from the chronology that there were a number of particular challenges in reaching a conclusion that the family were not entitled to continuing healthcare free of charge. *This includes, who is responsible for completion of the CHC assessment and miscommunication and misleading information about CHC.*

16.8.21 Whilst in July ACS visited the couple and it was noted that they would be 'self-funders' for care, it wasn't until August that Sarah's daughter raised the issue of CHC explaining that she was looking into it and that her GP didn't seem to know about it. A month later, Ann "requested support to apply for NHS Continuing Healthcare, and asked what would be involved in this process and what help they might receive". This raises a question as to who is responsible for completing such a checklist, is it a professional or a family member. Further email traffic between the family and social care suggests it is the family, when a message is sent to the family "Also stating that he had arranged for a senior SW to support him (Samuel) to complete the CHC check list for her mother. It wasn't until October that a senior social worker attended to complete the CHC checklist. At that point the list was left with Samuel to look through owing to him not wanting to answer questions in front of Sarah.

16.8.22 Government guidance says, "The checklist can be completed in by a variety of health and social care practitioners, so long as they have been trained in its use".[58] This exchange of emails suggests a need for clarity as to whose responsibility completion of CHC checklist is?

16.8.23 The same guidance also makes observation as to the role of the individual in completing a checklist and states "Where the individual concerned has capacity, their informed consent should be obtained before completion of the Checklist". In Sarah's case the notes do not describe the status of her capacity or suggest the need to test it in accordance with the Mental Capacity Act. On the one hand the daughter says in September that 'mum is unaware there is anything wrong with her' and on the other hand in October the notes record that Samuel said he felt uncomfortable in answering questions in front of her. This caused a delay, and the list was left with him to complete.

[58] Source: https://www.gov.uk/government/publications/nhs-continuing-healthcare-checklist (Accessed June 2020)

16.8.24 The dialogue between family and ACS continued throughout October 2018, the apparent issues being the care required for Sarah and ultimately who was going to pay for that care. In making that determination completion of the CHC, whether a full CHC assessment or a Fast-Track CHC could be completed. To consider the relevance of these points it is necessary to consider the NHS Continuing Healthcare Checklist government guidance in further detail.

16.8.25 At an early point of the guidance, it states "the Checklist threshold at this stage of the process has intentionally been set low, in order to ensure that all those who require a full assessment of eligibility for NHS Continuing Healthcare have this opportunity." It continues "There are two potential outcomes following completion of the Checklist:

- a **negative** Checklist, meaning the individual does not require a full assessment of eligibility and they are not eligible for NHS Continuing Healthcare; or
- a **positive** Checklist meaning an individual now requires a full assessment of eligibility for NHS Continuing Healthcare. It does not necessarily mean the individual is eligible for NHS Continuing Healthcare.

16.8.26 The guidance also provides guidance as to when a checklist is not required as "The individual has a rapidly deteriorating condition and may be entering a terminal phase – in these situations the Fast-Track Pathway Tool should be used instead of the Checklist" This can only be completed by an appropriate clinician and not by social care professionals.

16.8.27 From a family point of view, they expressed a view that she met the criteria for a fast- track approach, providing a view as to Sarah's deteriorating condition and her belief that she was approaching end of life. She listed a number of criteria as laid out in the government guidance such as; She is struggling to eat - the ability to swallow is going; she cannot toilet, wash or dress unaided; she cannot be left unattended; her level of comprehension is reducing and she cannot perform simple tasks such as unfolding a newspaper; she is losing the power of speech - is usually unintelligible; she imagines people and events.

16.8.28 On exploring the determination of life expectancy, there is a separate and specific Government guidance. [59] This states that an appropriate clinician, (not a social care professional) must complete the assessment and that such a person is defined as; a) responsible for the diagnosis, treatment, or care of the individual under the 2006 Act in respect of whom a Fast-Track Pathway Tool is being completed; and b) a registered nurse or a registered medical practitioner.

16.8.29 A view put forward by the family that a judgement about eligibility is determined by a three-month life expectancy. The guidance makes it clear this is not the case "strict time limits that base eligibility on a specified expected length of life remaining should not be imposed". What we know now from the GP's perspective is that Sarah was not close to end of life during the relevant period.

16.8.30 Communication with the family proved challenging for ACS during this time, with conflicting messages to the service as to how he was coping. ACS had determined that there were three LPA's, Samuel and both children and willingly engaged with them all by phone, by email and also making offers to carry out videoconferences to accommodate the daughter who lived abroad. This is recognised as positive practice by ACS, but perhaps also problematic that required an instruction to professionals to cease email communication with the family later in the relevant period. It struck the panel representative a more co-ordinated and planned approach when dealing with such situations including agreeing who is the lead family member would be beneficial to all parties.

[59] Source: https://www.gov.uk/government/publications/nhs-continuing-healthcare-fast-track-pathway-tool (Accessed June 2020)

16.8.31 During the latter stages of the review, the panels attention was also drawn to the 'Jointly App'[60], commissioned by CarersUK that is designed to make "caring easier, less stressful and more organised by making communication and coordination between those who share the care". The panel agree that such developments are welcomed and have the potential to assist communication between carers.

16.8.32 In order to seek resolution on the dilemma of CHC and the needs of Sarah and Samuel, a meeting was arranged by HoSF to take place at the family home in October with ACS present. Unfortunately, the meeting was cancelled by (the son) and ACS could not attend the re-arranged meeting. The IMR notes that the outcome of the meeting was not known, yet HoSF notes that ACS were informed of the outcome, which was that the family did not meet the threshold for local authority funded care and that they had been provided with details of agencies to assist. Given that ACS had requested that ANC do not contact the family until after the outcome of this meeting and given how thorny this issue had become, it seems that the outcome of any such meeting ought to have recorded and if not, followed up by a lead ACS professional. The subject of record keeping is subject to an individual agency recommendation.

16.8.33 Following discussion with the ACS panel representative, it was also acknowledged that there was a missed opportunity to signpost them to 'Beacon', an independent organisation that provides; 'free expert advice and affordable representation for families who are struggling to navigate the maze of NHS Continuing Healthcare'. [61] This independent view may have proved beneficial to the family and also ACS to ensure all parties had a common understanding of the situation at the same time. All staff have been reminded about this independent advocacy service and it features within local training.

16.8.34 From early November, the volume of communication with the family diminished, with ACS providing information in respect of support and respite for Samuel. ACS offered to have support organised by the local authority by a provider that would accept LA rates. However, this would be on the understanding that charges would be passed on to Sarah and Samuel. It seems over the following months the family made alternative arrangements with a 'ceasing note' being completed on the 6th December effectively stopping further active involvement.

16.8.35 ACS has made a single agency recommendation in respect of assisting carers who are self-funding and acknowledging a missed opportunity to refer the family to independent advocacy.

Support and Co-ordination

16.8.36 Notwithstanding the challenges of CHC and managing family expectations, examination of the chronology shows that ACS were proactive in offering support such as a sitting service, as well as signposting to care agencies and offering to refer to brokerage to secure care at local authority rates. ACS were working with Sarah and the family during a period when several other agencies were also working with them. There is evidence of open lines of communication, with the GP, HPFT and HoSF.

16.8.37 As noted at 16.5.28, ACS were invited to a multi-disciplinary meeting called by HoSF. This raised a question as to whether there was or ought to have been a lead agency. At this time, there were ten agencies involved and arguably HoSF were taking on a lead role, though not all agencies involved were invited to the MDT. However, one may argue that ACS were taking

[60] Jointly; An application created by carers for carers. It is designed to make caring a little easier, less stressful, and more organised. It combines group messaging with other useful features including to-do and medication lists, calendar and more.

[61] Source: Beacon CHC | Free advice | Affordable advocacy - Beacon (Accessed December 2020)

a lead role, given they had asked ANC to refrain from making contact with the family. The situation in this case is unclear, with no clear lead agency providing co-ordination. It is also arguable ACS would not necessarily be a lead agency as neither Sarah nor Samuel fell into the category of requiring statutory support.

16.8.38 Given this lack of clarity, it would appear there was a missed opportunity to consider whether a lead agency ought to be determined, or whether there ought to be a partnership mechanism/framework where such complex cases, involving multiple partners can contribute to a planned response. However, whilst an individual agency recommendation was made regarding the need to continue improving joint working, the panel's attention was drawn to two developments introduced since this tragedy.

- The first is Hertfordshire Safeguarding Adults Board Multidisciplinary Guidance for Complex Cases 2020 that is a "guide for practitioners working with adults outlining the importance of adopting a multi-disciplinary approach to practice, particularly when working with people with complex needs or circumstances".
- The second is complimentary local guidance on scheduled multi-disciplinary team meetings along with referral forms into a process for each of the four localities that make up West Hertfordshire. These locality MDT meetings have core members that include GP's, consultant geriatricians, social care and others, and opportunities for other agencies such as those involved in this case to attend. These are designed for cases that may be described as complex and or high risk and may require input from multiple agencies and provide a framework to consider circumstances such as Sarah's and to "*to link up case work in a cohesive way and avoid duplication*".

16.8.39 Both these are significant developments, good practice and currently being used by partners.

Summary Analysis in Respect of Keylines of Enquiry

Term 1: Information Sharing

16.8.40 ACS worked with a number of agencies and family, through email and telephone conversations, though recognised the need to continue to improve joint working in an individual agency recommendation. However, since the tragedy new strategic and local guidance has been introduced, that provide the information and mechanisms to call multi-disciplinary team meetings for cases such as Sarah's and Samuels. The challenge remains to ensure professionals are aware of the process and recognise the complexity of cases such as this and use the protocols.

(LO16) Learning opportunity: To improve partnership co-ordination in respect of complex cases.
Individual Agency recommendation also refers: *Continue to improve on joint working with partnership agencies both statutory and in voluntary sector.*
+
Response*: Introduction of (a) Hertfordshire Safeguarding Adults Board Multidisciplinary Guidance for Complex Cases 2020 and (b) Recently introduced and scheduled locality- based MDTs.*

16.8.41 Whilst there was a comprehensive chronology, there were apparent opportunities to improve record keeping (16.5.7 & 16.5.27).

(LO17) Learning Consideration/ Opportunity: *ACS to improve local record keeping.*
Individual agency recommendation refers: *Improve recording on ACSIS, encourage staff to attend "Good Recording" training course already offered by ACS Learning and Development."*

Term 2: Key line of Enquiry 2-Assessment and diagnosis

16.8.42 On dealing with Sarah, a number of opportunities to improve practice were identified by the IMR author. It was noted that workers were not able to see Sarah alone. There is no record of the reasons why, suggesting the need for improved professional curiosity and to have found opportunities to have explored Sarah's mental capacity, ensuring that Sarah's view was actively sought in accordance with safeguarding principles.

(LO18) Learning Consideration/ Opportunity: *ACS to ensure that staff involve clients as much as possible in decision making, seeking their views and test their capacity as required.*
Individual agency recommendations refer:
- *Ensure staff members attend training in relation to Mental Capacity and Best Interest decisions.*
- *Staff to attend all safeguarding training courses both face to face and on I-Learn as well as ongoing refresher courses.*
- *Staff to continue carrying out assessments and care and support planning that are person centred in line with the Care Act.*

+
Local Learning: *Hertfordshire Safeguarding Adults Board Learning Bulletins on 'Professional Curiosity' October 2020 and Spring 21*

16.8.43 Linked to the learning opportunity above, is the fact that Sarah did not have a 'connected lives assessment' nor any 'risk assessment'. Such assessments may have resulted in offers of support or other action, and the fact that they were not completed may in itself have been a barrier to support.

16.8.44 Upon exploration as to how the necessity and quality of 'connected lives assessments' and 'risk assessments' is overseen, the panel learned that in ACS, there is a Connected Lives Board and a Practice Management Board, that oversee monthly audits of assessments. The circumstances and learning of this review will be presented to these boards.

(LO19) Learning opportunity: *To seek assurance that relevant assessments including connected lives assessments and risk assessments are completed.*
Individual Agency Recommendation refers: *Regular supervision to take place where complex cases can be discussed.*
Governance*: Connected Lives Board and Practice Management Boards oversee CLA completion rates that now includes monthly audits*

16.8.45 Whilst domestic abuse was not apparent, we know that risk assessments were not completed and that no-one was asked about DA. Whilst systemic invisibility of DA in the elderly had been the subject to an individual agency recommendation for ACS staff, following panel discussions on 'routine enquiry', ACS has agreed the need to adapt their protocols to include questions on domestic abuse.

(LO20) Learning Consideration/ Opportunity: *ACS to raise awareness of the potential for domestic abuse in relationships between the elderly.*
Individual agency recommendations refer: *Improve awareness of domestic abuse for staff.*
Recommendation 2: *ACS to adapt their risk/needs assessment protocols to include a question/prompt on domestic abuse.*

16.8.46 Samuel's presentation to ACS was different to that portrayed by his family, resulting in the delay of a carer's assessment. He explained and it became clear through the relevant period that the volume of agencies involved was difficult for him to manage. He was described by his family as being "unhappy, lonely and depressed" and it is therefore reasonable to conclude that the caring responsibilities were burdensome. However, Samuel declined offers of assistance and in some respects, one may conclude that Samuel himself became a barrier to support.

Term 3: Key line of Enquiry 3-Contact and Support from agencies

16.8.47 ACS made offers of support to Sarah and Samuel including a free sitting service. Upon realisation that savings precluded free care, they signposted the family to other care agencies and offered support for brokerage that would secure care at local authority rates.

16.8.48 A point of contention for the family was the continued healthcare assessment and also the 'fast-track' scheme. The question as to the role of the family in completing a CHC became unclear. Whilst a senior professional did take the lead, ACS has made a single agency recommendation and the panel representative also identified a missed opportunity to refer the family to 'Beacon', a specialist advocacy service that may helped avoid some of the misunderstanding. All staff have been reminded of this service and it features in local training.

(LO21) Learning opportunity: *To remind staff of the need to signpost family to independent advocacy.*
Individual agency action refers: *All staff have been reminded of 'Beacon' and it features in local training.*
Individual Agency Recommendation refers: *ACS should be more proactive in supporting service users and their carers who are self-funding to access services more effectively*

16.8.49 Whilst lines of communication were open with the family, this may have also contributed to misunderstanding. ACS had determined there were three LPA's, Samuel, and his children. It was therefore a difficult set of circumstances for ACS to manage, and it struck the panel as an opportunity to ensure a more co-ordinated and planned response to communication, perhaps through a lead family member.

(LO22) Learning opportunity: *To improve the communication with families supporting those living with dementia.*
Recommendation 4: *ACS in dealing with complex family dynamics, review whether appointing a lead family member is appropriate.*

16.8.50 The panel recognised that the newly developed 'Jointly App' commissioned by CarersUK as worthwhile signposting family members to create their own circle of care for a person being looked after.

16.9 Hertswise

16.9.1 Analysis has been completed by reference to an agency chronology and through meetings with the panel representative.

16.9.2 Sarah and Samuel were referred to Hertswise on multiple occasions. Initial contact was from Ann to seek advice in January 2018 that resulted in agency contact early in February. Thereafter, referrals were received from EMDASS, GP and Carers in Herts. They engaged primarily with Samuel and Ann during the relevant period, via phone calls and email as required. Assistance may be broken down into a number of themes including; Nature of Circumstances; Advice & Guidance and Practical Support; co-ordination with other agencies.

<u>Nature of Circumstances</u>

16.9.3 Whilst contact was over a period of a year, most of the engagement was in the latter half of 2018. Taking an overview of the contact through the year, the initial contact by Ann was to seek advice and during that initial contact she described Samuel as being stubborn and not welcoming help. This is reflected in Hertswise's first contact with Samuel in February when he declined help and explained that Sarah only had a few memory problems. It is open to

speculation at this point. as to whether Samuel was minimising issues, was just reluctant to receive help and/or in denial.

16.9.4 It appears situation deteriorated through 2018, when in June EMDASS and the GP referred them to Hertswise to assist with completion of 'attendance allowance' and 'Council Tax Reduction' forms. Samuel was again reticent to accept help, explaining that Sarah became upset talking about dementia. Hertswise gave appropriate advice, explaining that as he had power of attorney, he could complete the forms. He said that he would think about it.

16.9.5 It may be argued that Samuel's reluctance to accept support was in itself a barrier requiring further exploration. There are a number of articles that explore this phenomenon. An article published in International Psychogeriatrics concluded that '*Barriers included denial, stigma and fear, lack of knowledge, normalization of symptoms, preserving autonomy, lack of perceived need, unaware of changes, lack of informal network support, carer difficulties, and problems accessing help. Facilitators included recognition of symptoms as a problem, prior knowledge and contacts, and support from informal network*'. The point herein is recognition of potential barriers, as well as individual's rights to decide what to accept or follow up, but something that merits exploration by professionals.[62]

16.9 6 Upon exploring the training offer for staff, it includes Safeguarding, Care Act and Mental Capacity and more recently additional development training has been made available including the webinars on professional curiosity highlighted elsewhere in the report.

16.9.7 Home visits in August, September and October shine a light on the circumstances at that time. Sarah was becoming more anxious, more and more reliant on Samuel for daily activities such as washing and dressing. Her ability to communicate was also diminishing and it was noted that Samuel also had difficulty communicating with her, owing to her behaviour.

16.9.8 It was noted that Samuel was becoming more stressed. He was reluctant to leave her at any time and was becoming increasingly worried about her wandering. Whilst it was noted that he had support from family, it is also apparent that he himself had little opportunity to talk freely, as he was worried about being overheard by Sarah and upsetting her. It was observed that when the opportunity arose and discussion took place in respect of respite care, he felt guilty.

Risk Assessment

16.9.9 An holistic needs assessment was carried out that includes variety of care and environment risks. However, there was no specific reference or prompt to consider DA, that arguably adds weight to concerns about systemic invisibility of DA occurring in the elderly. The panel representative has agreed that such needs assessments are adapted to include a question/prompt on domestic abuse.

Advice and Guidance

16.9.10 Hertswise has engaged with Samuel and also with the couple's daughter, throughout 2018, early in January and again in June, July and August, providing appropriate advice on a number of subjects that included, signposting Samuel for a carers assessment with social carer, where to get further support such as Crossroads and advising on subjects such as Power of Attorney (POA) and completion of applications for; -Attendance Allowance (AA); - Council Tax reduction (CTR); -Carers Allowance (CA); - Disabled Facility Grant. In so doing, Hertswise have listened to Samuel and the daughter Ann to develop a trusting relationship, offering a breadth of support.

[62] Source: Persistent barriers and facilitators to seeking help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and people with dementia | International Psychogeriatrics | Cambridge Core (January 2021)

Practical Support

16.9.11 On exploring the level of support that is available with the panel representative it was learned Hertswise may offer Monday to Friday daytime attendance but are unable to offer any night-time cover.

16.9.12 Hertswise have provided support in terms of respite, visiting on three occasions (26/9, 4/10 & 26/10). The first visit may be considered as conversational and assessing Samuels needs, with the following two visits by a locality worker being supportive spending time with Sarah drinking tea and going through photographs. On one of these occasions, Samuel went out for 15 minutes, but was concerned to return home quickly.

16.9.13 During the first visit, Hertswise observed that Samuel appeared very stressed and needed lots of support and that adult care services had recently been in contact and ANC had visited. They also learned that the son visited once per week, but that he could not get a break owing to Sarah wandering. Samuel was provided details of carer agencies to assist with practical support such as bathing and also signposted to the Dementia Helpline regarding difficulties in communication.

Co-ordination with other agencies

16.9.14 The question of how Hertswise co-ordinate with other agencies was explored in a meeting between the chair and panel representative, who explained that Hertswise are a lead partner for a number of agencies including the Alzheimer's Society, Carers in Herts, and ANC. This enables sharing of information by using one database 'Charity log', across these agencies if those agencies are not using their own database. It is not shared across other agencies.

16.9.15 They have acted proactively following the initial visit, alerting social care of their observations in order to seek further respite, but note they were not fully aware of all the agencies involved nor part of any MDT meetings, reflecting there were opportunities for the whole partnership to co-ordinate more effectively to support Sarah and Samuel. This links with the need for enhanced professional curiosity noted at 16.9.5 & 6.

Summary Analysis in Respect of Keylines of Enquiry

Term 1: Information Sharing

16.9.16 Hertswise, are a lead partner for a number of agencies including the Alzheimer's Society, Carers in Herts and ANC that enables sharing of information across those agencies.

16.9.17 Hertswise were referred to by the GP and EMDASS to assist with completion of various forms and offer some respite. Whilst they became aware of ANC and social care involvement, they were not involved in any MDT meetings.

Term 2: Key line of Enquiry 2-Assessment and diagnosis

16.9.18 Hertswise has observed that Samuel appeared stressed and anxious, requiring support to look after Sarah.

16.9.19 No safeguarding or issues in respect of domestic abuse were apparent. It seemed that Samuel was anxious to look after his wife avoiding conversation about dementia to prevent distress to Sarah. Whilst DA was not apparent, current needs/risk assessments do not ask or prompt consideration about the risk of DA. The agency has agreed to amend its protocols to include routine prompts on DA.

(LO13) Learning Consideration/ Opportunity: *Develop risk assessment protocols to ask routine screening questions on domestic abuse and ensure risk assessment takes place in private.*
Recommendation 2: *Hertswise to adapt their risk/needs assessment protocols to include a question/prompt on domestic abuse.*

16.9.20 It may be argued that Samuel's reluctance to accept support was in itself a barrier, meriting further exploration improved professional curiosity at the time. It is noted that the subject of improved professional curiosity has been the subject of work by Hertfordshire Safeguarding Adults Board (16.3.19) that Hertswise have accessed since the tragic circumstances of this case.

(LO23) Learning Opportunity/Consideration: *Recognising reluctance to accept support as a barrier requiring an investigative mindset and professional curiosity.*
Response*: The subject of Professional Curiosity has subsequently been subject to and continues to be subject to Learning Bulletins by Hertfordshire Safeguarding Adults Board that supports annual training programme.*

Term 3: Key line of Enquiry 3-Contact and Support

16.9.21 Whilst unaware of all of the agencies involved with Sarah and Samuel, they are a lead agency who worked closely with Alzheimer's Society, Carers in Herts and ANC and engaged with Adult Care Services.

16.9.22 They also developed a trusting relationship with Samuel and his daughter, offering practical support and assistance in the completion of various forms.

16.10 Crossroads

16.10.1 An IMR has been completed that highlighted a number of learning opportunities, that include a timeliness of service, systems of monitoring and record keeping.

Timeliness/Delays in Support

16.10.2 There was a delay between the referral from Carers in Herts on 15th August until assessment on the 20th November, even though Carers in Herts chased Crossroads on the 10th September. The IMR author has noted that the initial referral reported that "carer desperately needs some support". This delay would appear to have occurred in part owing to different systems of monitoring, whether self-referral or a professional referral, only self-referrals being closely monitored by the client services team. Furthermore, records at the time were maintained on spreadsheets that did not automatically send alerts. Acknowledging this, two single agency recommendations were made and have been implemented.

- Review of intake processes to improve oversight.
- All waiting list entries to carry a risk and urgency rating.

Now all clients are now overseen by client services and on receipt of a referral, contact is made with a client and urgency is determined and a clear instruction is given about the timeframe for support.

16.10.4 Once contact was made on 16th November, a home visit was carried out four days later on the 20th November four days. At this visit an initial assessment of need takes place. The details of this visit are not available, and it seems that records of visits used to be paper based and are no longer available. Practice has subsequently developed, and a new online system is now in place.

16.10.5 Further contact was made in December and support was declined as Samuel and Sarah's daughter was home from Australia and a request was made for support to commence in January.

16.10.6 In January Samuel again asked for the service to be postponed as his daughter was still in the UK and it was arranged for Friday 8th March when the first supportive visit took place. Unfortunately, the assigned carer left the organisation and could not attend on the following Friday. The agency called him on the 19th and owing to shortage of volunteers placed Samuel on a waiting list.

16.10.7 Moreover, Samuel's specific requests to have the same support worker, on the same day and time of the week proved problematic though understandable from a carer's and cared for point of view. Indeed, one may argue that having a familiar face visiting is even more desirable when dealing with someone who has dementia. Carers are now always allocated to the same worker, the same day and same time each week.

16.10.8 Upon exploration with the panel representative, it seems there was a significant shortage in volunteers. Crossroads has now set up a charitable fund and volunteer service for welfare visits where staff support is in short supply.

16.10.9 Whilst Samuel declined support as his daughter was visiting, the IMR author reflected that it may have been advisable to accept care during this time, to have enabled him to spend some quality time with his wider family, alleviated from immediate caring responsibilities. This being the case, the question arises as to how one may persuade a client to accept such help. This observation is not subject to a single agency recommendation. However, the IMR also comments about a lack of awareness of the number of agencies involved in the case and the benefits of adopting a multi-disciplinary approach. During panel discussions, induction practice has now been adapted to ask clients/carers what agencies they are working with. This now provides the basis from which to either approach other agencies or using the using the "HSAB Multidisciplinary Guidance for Complex Cases 2020" as a vehicle to bring agencies together to address specific concerns.

16.10.10 The benefit of such an approach may also have been the ability to liaise with another agency on occasions where practical matters arise, such as when they were unable to fulfil an obligation to attend and provide support, such as on Friday 15th March 2019.

Risk Assessment

16.10.11 Crossroads carried out a holistic assessment of need, that examines s number of these that includes, care risks and environment risks. A total of over seventy features are subject to assessment. Whilst the original assessment is not available and all assessments are now completed on an App, there is no space or prompt to actively consider wider concerns, be that regarding domestic abuse or safeguarding. It may be argued that the absence of a prompt to consider the possibility of such concerns adds to the ongoing systemic invisibility of DA occurring in the elderly.

Summary Analysis in Respect of Keylines of Enquiry

Term 1: Information Sharing

16.10.12 Notwithstanding a referral from Carers in Herts describing a pressing need for support, there was a delay owing to systems issues of prioritisation and record keeping that are subject to individual agency recommendations.

(LO24) Learning Opportunity/Consideration: *Improvement of intake processes to ensure effective prioritisation.*
Individual agency recommendation refers: *Review of intake processes to improve oversight.*
Individual agency recommendation refers: *All waiting list entries to carry a risk and urgency rating*

16.10.13 It was apparent that Crossroads were unaware of the breadth of agencies involved and whilst they now ensure that clients/carers are asked who else they are working with, their IMR observed that it would have been helpful to adopt a multi-disciplinary approach. During the review process the panels attention was drawn to "HSAB Multidisciplinary Guidance for Complex Cases 2020" and complimentary local guidance on scheduled multi-disciplinary team meetings along with referral forms into a process.it is suggested this is an appropriate process for agencies to utilise for drawing together agencies.

(LO16) Learning Opportunity/Consideration: To improve partnership co-ordination in respect of complex cases.
Response*: Introduction of (a) Hertfordshire Safeguarding Adults Board Multidisciplinary Guidance for Complex Cases 2020 and (b) Recently introduced and scheduled locality- based MDTs.*

Term 2: Key line of Enquiry 2-Assessment and diagnosis

16.10.14 Notwithstanding a referral from Cares in Herts describing a pressing need for support, there was a delay owing to systems issues of prioritisation and record keeping that are subject to individual agency recommendations.

16.10.15 A number of agency recommendations around the internal processes have been made and implemented. This includes prioritisation and all clients whether self-referred or agency referred being overseen by client services.

16.10.16 At the time, assessments were paper based and the assessment for Samuel and Sarah was not available. Now all assessments are completed via an App. They are retained online. Whilst very comprehensive in nature, there are no prompts to consider domestic abuse or safeguarding.

(LO25) Learning Opportunity/Consideration: *To expand the prompts within the risk assessment to consider safeguarding and/or concerns around domestic abuse.*
Recommendation 2*: Crossroads to adapt their risk/needs assessment protocols to include questions/prompts on domestic abuse.*

Term 3: Key line of Enquiry 3-Contact and Support from agencies

16.10.17 On considering Samuel's reluctance to accept support whilst his daughter was visiting from abroad and what may have been beneficial to Sarah and Samuel, the agency observed that they were unaware of the number of agencies involved. See 16.10.12 and 16.10.13.

16.11 Alzheimer's Society (AS)

16.11.1 Analysis has been completed by reference to an agency chronology and through meetings with the panel representative.

16.11.2 At the time of engagement with Sarah and Samuel AS were primarily recording their interactions on the HPFT records system, there being limited commentary on the AS system. This analysis must therefore be seen in conjunction with the EMDASS analysis. A separate IMR was not submitted.

16.11.3 It was learned that there were two elements to the work of AS. The first element being their work at HPFT (EMDASS service) and the second element being the community-based service. The AS chronology supplied only deals with the second element of AS work, from 5th June 2018 when records were transferred to AS systems and one phone call on 25th September 2018, before a letter in January the following year and closure of the case.

16.11.4 When considering AS working with EMDASS, there was a 38-week period of engagement within the EMDASS pathway, during which the AS engage with clients for post diagnosis support. In Sarah's case, no contact was made from the 5th February 2018 through to the 5th June 2018, as she was not deemed a priority case.

16.11.5 Thereafter, the case in closed to the first element of AS support and the matter was transferred to the community dementia advisor team for supporting Samuel, as no consent was given by Sarah to receive support from the AS community dementia support service. There is limited personal contact from that team to Sarah and Samuel, with a phone call in June, a letter on the 4th January 2019 and the case being closed on the 1st February 2019.

16.11.6 An internal review was in progress before the incident took place took that subsequently resulted in changes to record keeping discussed below and the operating model that now sees the same dementia support worker/dementia adviser holding cases from their initial referral through EMDASS pathway and beyond, depending upon the needs of the service user. This revised pathway described at 16.2.3-16.2.4, in effect means that once diagnosed, clients are closed to EMDASS and open to AS. This is recognised as improved practice providing consistent support for the end client.

Record Keeping

16.11.7 As a result of the internal review noted above, AS have made changes to their record keeping including the introduction of their own *client record keeping system*. Previously they were reliant on HPFT patient record systems as opposed to their own. This is seen as a positive step considering the challenges in unpicking a chronology from one system that reflects interactions from two organisations.

Risk Assessment

16.11.8 On exploring how the determination of Sarah's priority had been arrived at, the panel learned that her 'low priority' was owing to the assessment she had a supportive husband and family with no reported no problems in caring. A higher priority would be given at the request of the memory nurse and marked on the risk assessment such as for those who had no support, were suffering from depression or had a history of falls. The initial assessment of priority made by a dementia adviser was based upon the EMDASS initial risk assessment made by the HPFT memory nurse, and any new or additional information that arises from the initial telephone call with the service user.

16.11.9 We know that Sarah had been assessed on the 5th February 2018, but unknown to AS was that on the 6th February Sarah's daughter expressed concern her father was struggling to cope. This was known to the GP and social services. This poses the challenge of; the extent to which a carer is being candid, owing to pride, not recognising their own need, disguised coping or wishing to maintain control of circumstances and how professionals' probe to find out.

16.11.10 On considering how risk was assessed at the time. AS relied upon the initial assessment by the memory nurse in EMDASS. Processes have subsequently evolved, and two screening guides are now used during engagement. One is a tabular guide that as to when clients are

living alone or with a family and in each case summarise the level of support available and that may be needed. (Proactive Guide to Kit V2).

16.11.11 The second is a risk assessment priority Guide that describes the client's needs in terms of low, medium, or high. Within the medium risk categories are; choosing a care home, preparation and support for continuing healthcare, additional responsibilities such as carers own poor health. In Sarah and Samuel's case, we know that he had his own health issues and at various points in time other factors were present. Arguably their circumstances merited a medium risk rating. Within, the high-risk factors, it is noted carers breakdown and safeguarding risk feature. However, at the time of AS involvement, these factors were not clearly apparent to AS, as they were using information from within the EMDASS pathway and the community dementia support team did not have direct contact with Samuel, receiving no response to a letter.

16.11.12 Moreover, as risk is not static, it may be argued that the assessment of need and risk ought to be reviewed more frequently. Caregiver burden is widely recognised, Science Direct reporting, 'The demands and negative impacts of dementia caregiving are generally higher than nondementia caregiving' and that 'they also report greater employment complications, caregiver strain, mental and physical health problems, reduced time for leisure and other family members, and family conflict.'[63] It is therefore considered likely that any such strains may build over time. Recognising this, AS have subsequently changed their practices, using a 'keeping safe checklist' and recording a risk assessment *at each and every contact* that is recorded on their client record systems. This is seen as good practice.

16.11.13 The 'Keeping Safe Checklist' is broken down into three sections, health, and medical conditions, how the diagnosis of dementia affects the patient's wellbeing and accessing services safely. There are no overt questions as to domestic abuse or safeguarding. Upon exploration with the panel representative, the option of asking questions as to 'how the diagnosis of dementia affects the behaviour of a carer', is recorded as a separate part of the assessment and clients such as Samuel are asked 'how does living or supporting someone with dementia affect you?'. These questions may illuminate any changes in their thinking. Following further discussions between the panel chair and AS representative, the AS Head of Safeguarding has agreed that changes will be made to include 'observational prompts' regarding domestic abuse. This evolution is welcomed and will assist in removing the systemic invisibility of abuse discussed elsewhere within this report.

16.11.14 Mindful of hindsight bias, it may be argued that when considering the point "the extent to which a carer is being candid" there is a need for professionals to be alert to the possibility that clients and carers may not share all concerns for a variety of reasons, requiring improved professional curiosity and the use of a checklist. Looking for continual improvement, AS has also developed relevant webinars, the first 'improving professional curiosity' that began to be delivered in December 2020 and the second on domestic abuse in March 2021. Given that AS have not completed an IMR, but have reflected on practice, the use of this webinar is noted as a positive development. They have similarly introduced a webinar on domestic violence.

16.11.15 On exploring the infrequent contact with Sarah and Samuel, it was explained that AS adopts a person-centred approach, requiring AS to be respectful of service user's wishes and that it is fairly normal to speak with the carer. The service specification says "People with dementia will always be at the centre of everything we do – "We will work to ensure that their perspectives inform all our activities. We will enable people to maintain the maximum possible level of independence, choice, and control." Given the limited contact with AS, the recognised issues of carers burden for carers of dementia patients, it may be argued that infrequent contact and regular check in, could in itself be a barrier to securing support. The clarity in

[63] Source: Caregiver Burden - an overview | ScienceDirect Topics (Accessed November 2020)

operating procedures and demarcation between EMDASS and AS described at 16.11.6 will now ensure regular contact by the AS community service, and assessment via the 'keeping people safe checklist' before the case closes.

Summary Analysis in Respect of Keylines of Enquiry

Term 1: Information Sharing

16.11.16 AS work closely with HPFT, attending weekly MDT meetings (see HPFT) that memory nurses, occupational therapists, psychologists and speech and language therapists attend. This is seen as effective practice. They were not involved in any wider MDT meetings outside of the EMDASS/HPFT arrangements that were called for Sarah and Samuel.

16.11.17 An internal service review commenced before this incident, has clarified the pathways between EMDASS and AS, making it clearer who is responsible for supporting clients post diagnosis.

Term 2: Key line of Enquiry 2-Assessment and diagnosis

16.11.18 AS have conducted an audit of their systems and have made a number of systems changes. The assessment of risk/need and engagement was predicated on an initial assessment by HPFT (EMDASS). No direct questions in respect of safety or domestic abuse were asked, nor were there any concerns raised or apparent. AS now use a 'keeping people safe checklist' on every contact with clients, that in effect ensures a frequent review of circumstances.

16.11.19 Following discussions between the panel chair, AS representative and the AS Head of Safeguarding, it has been agreed that changes will be made to include 'observational prompts' regarding domestic abuse. This evolution is welcomed and will assist in removing the systemic invisibility of abuse discussed elsewhere within this report.

16.11.20 The panel also welcome recent webinars, the first on professional curiosity in December 2020 and the second on domestic abuse in March 2021 These are seen as positive developments that will add to the recommended changes to the 'keeping safe' checklist.

16.11.21 The changing practice to conducting a 'keeping safe' checklist at every contact is seen as good practice. At the final panel meeting, it was observed this will be a nationwide change across the Alzheimer's Society.

(LO26) Learning Opportunity/Consideration: *To encourage screening for domestic abuse by adapting the 'Keeping people safe checklist'.*
Recommendation 2: *Alzheimer's Society to adapt their risk/needs assessment protocols to include a question/prompt on domestic abuse*

Term 3: Key line of Enquiry 3-Contact and Support from agencies

16.11.22 AS worked with HPFT and were not engaged nor did they collaborate with any of the other agencies that were engaged with Sarah and Samuel at this time.

16.12 Hospice of St Francis

16.12.1 HoSF has provided an IMR and a copy of case reflection notes (CRN) that are based upon an in-house discussion with a number of professionals present that includes; Community Nurse Specialist (CNS), Head of Community Services, Director of Care (Chair), Physiotherapist, Head of Rehabilitation, two palliative care consultants, senior doctor, Head of In-patient Unit,

Director well-being and family support, Head of Integrated Governance and Social Work, Chief Executive Officer.

16.12.2 Sarah's GP referred her to HosF in late July 2018 for respite care. This was declined by the nurse on duty in the Palliative Referral Centre that is jointly run by hospices and the NHS, as hospices are there for people in the last days and weeks of their lives. A further referral was received from the GP on 3rd August for respite at home, this referral was accepted and sent to the Hospice of St. Francis. An out-patient appointment was made for Sarah for early August. At this consultation Sarah took part in the assessment together with Samuel, Sarah said that she was experiencing some practical problems and Samuel confirmed this and Sarah said that she was anxious about the diagnosis. The assessment concluded some physiotherapy might assist Sarah's mobility. A carers assessment was offered to Samuel, and he agreed to consider this for the future. The HoSF determined in their case reflection notes "include a further trigger for the care team" to check whether Samuel would reconsider an in-depth exploration of carers feelings and carers needs and what could be helpful. This check was completed at each review and/or point of change/deterioration. Samuel continued to say he would consider this in the future. This continued checking is recognised as effective practice.

16.12.3 Sarah and Samuel attended a further outpatient appointment for physiotherapy. Discussion about how they were at home, and whether community palliative care nursing support from HoSF would be helpful together with complimentary therapy was a consistent feature of discussion at each review from August to December. Samuel declined further support from HoSF however he did follow up the information discussed to organise practical care at home from a private carer agency and services offered by the local authority and potential care homes. Samuel and Sarah said that their son who lived locally was supportive. When the son contacted the hospice, he said the hospice should do more and did not agree (when discussing this with the hospice staff) that his father could decline this care. The expectation was that the Hospice could provide the care he wanted for his father and mother by admitting Sarah owing to the longstanding support that Sarah and Samuel had in fundraising for the hospice.

16.12.4 This was not possible at the time as Sarah was not close to end of life. Hospice beds in Hertfordshire operate at 85-94% occupancy meeting demand for people in the last days and weeks of life and/or for active symptom control, palliative rehabilitation, to prevent unplanned acute hospital admission and/or to facilitate discharge from acute hospital. HoSF like all local hospices does not have the capacity to offer a bed for respite care to patients.

16.12.5 Exploring this further with HoSF, it became apparent that they can safely offer an in-patient bed to people with advanced dementia who <u>do not have</u> the symptom of wandering when this diagnosis is co-morbid with other life-limiting diagnoses at the end of life, and to people in the end stage of dementia. Sarah was never determined at the end stage of dementia.

16.12.6 Notwithstanding HoSF's conclusion regarding Sarah not being at end of life, her situation was subject of at least weekly consideration in the period mid-September through to December. Features from the chronology include; (a) monthly liaison meetings with GP's; (b) family engagement; (c) hosting of a professionals meeting; (d) engagement across agencies.

<u>Monthly liaison meetings</u>

16.12.7 Monthly liaison meetings provide an opportunity for specialist nurses to update GPs on the outcomes of referrals made to HoSF and to discuss care of the patient from a GP and HoSF perspective. Upon further exploration, it was explained that HoSF take part in 'Gold Standard Framework' meetings that enable good practice and improved quality of care around palliative and end of life care irrespective of patient's diagnosis. These meetings are held every 4 -6 weeks and involve GPs, palliative care team and district nurses and other health care

professionals. These meetings enable discussions and sharing of information from the HoSF and GP perspective.

Family engagement

16.12.8 HoSF engaged regularly with Samuel and their son, often more frequently than once per week and on occasions multiple phone calls on the same day to both Samuel and son. David emailed in late September and a feature of subsequent contacts with family was that the belief that Samuel was not coping well and was doing more than it was reasonable for a father to do and that the son wasn't able to help him or his mother more. He felt he was advocating on behalf of his father to get help for them both.

16.12.9 Following the contact on the 26th September 2018, where he expressed a concern that Samuel was "finding the situation difficult to deal with", HoSF co-ordinated a family meeting on the 4th October, where it was observed that Sarah was not able to engage to the same extent as previously, but where it was also clear there was a difference in opinion between Samuel and his son who did not think Samuel was coping and was doing more than was reasonable. However, Samuel only agreed further assistance would be helpful, he did not want to transfer care to a home. It is noted that this difference of opinion featured within other agency dealings with the family.

16.12.10 The outcome of this meeting was to offer practical help with guidance with continence, telecare (door and bed alarms). Support with Adult Care Service (ACS) and ANC communication

16.12.11 The contacts throughout October and November, included arrangements for a further meeting with the family and other professionals, updates from the son as to how matters were developing, the responsiveness of HoSF in sending various forms off for respite to ACS and also engagement and follow up in respect of how sleeping medication was helping. The chair notes that the chronology provides a comprehensive record of engagement.

Professionals Meeting and Wider Professionals engagement

16.12.12 Following a telephone call from HoSF to Samuel on the 11th October 2-18, the HoSF community nurse service (CNS) asked Sarah and Samuel about holding a meeting to review care and outlined who would be invited. HoSF worked hard to secure a convenient date for all involved including the family, HoSF specialist nurse, their consultant, ANC and ACS. Even though neither ANC nor ACS were able to attend on the 24th October, the hospice decided to go ahead with the meeting owing to concerns expressed by the son. At this meeting practical matters such as medication to assist with sleeping patterns and the day care option were discussed and some measures were subsequently undertaken such as sleeping medication. The CNS agreed to liaise with ACS and ANC post meeting via email and spoke with ACS re referral for day care.

16.12.13 It is difficult to assess the impact of ANC or ACS not attending on Sarah, Samuel, and wider family, but it is suggested this could risk undermining family confidence in the system.

16.12.14 Whilst on the one hand, it is clear that HoSF have been proactive in attempting to set this meeting up, the overall chronology indicates that there were ten agencies engaged with the family at this time. Ultimately only HoSF attempted to co-ordinate a multi-disciplinary meeting and that in this case only HoSF attended. Whilst it may not have been possible or desirable to have wide ranging professionals meeting with the family, it seems that such broader meetings merit further consideration as does who ought to take the lead in co-ordinating these types of meeting. HoSF on conducting their own 'case reflection meeting' also made observations around relationships with other agencies and multi-disciplinary meetings, recommending "Regular Spring Centre Multi-Disciplinary Team meetings/North West Herts

MDT discussion and documentation for complex cases ensuring social work team aware of situation".

16.12.15 The chair has been informed of the subsequent development of the integrated community team at HoSF that ensures social workers are made aware of all complex cases, encouraging case discussions in a timely manner. This is a positive development.

16.12.16 Later in the year, (13/12/18), Sarah's son phoned HoSF and reported that Sarah was deteriorating, not recognising Samuel. The intention was to plan a family meeting with other services in January. This meeting did not take place. On exploration, the CNS called David back on the 3rd January who explained that his sister had persuaded Samuel that Sarah needed care. The family explained they had been in touch with Carers in Herts, were planning to speak to social care and also visit a day centre. As family seemed to have plans re care and future plans a meeting was not deemed necessary.

16.12.17 The efforts of HoSF to co-ordinate the meetings noted above, is also reflected in wider information exchange and collaboration with agencies, such as checking in with the GP about medication and also with ACS about the securing of respite/day care that the HoSF were not able to provide. This is recognised as being proactive and also sensitive to the needs of Sarah and her family.

Assessment of Risk and Need

16.12.18 It was clarified that the HoSF uses a Carers Support Needs Assessment Tool (CSNAT) for its carers assessments and an initial patient assessment. The CSNAT invites responses by the carer to fifteen questions across a range of subjects, designed to assess the level of support required to care for the relative. HoSF does not act on behalf of the local authority to complete a statutory carers assessment (section 10 of the care act). The hospice undertakes a carers assessment in relation to the specialist and palliative care that a patient needs where the carer has capacity, and it is jointly decided that they will be providing any of that care.

16.12.19 This 'needs assessment' covers; physical assessment and mobility; functionality; psychological assessment; social assessment; carer information; medication assessment; patient entitlements; future care planning. In Sarah and Samuel's case, there was no indication that a safeguarding assessment was required and there was no cause given to believe that Samuel did not have capacity and was able to care for his wife.

16.12.20 HoSF consider both patient and carer safety and wellbeing, explaining that in Sarah's case, this related to the risk of falls, wandering, self-care as well as eating and drinking. In Samuels case, considering resilience, ensuring sufficient sleep. They advised, signposted, and attempted to facilitate other care that was available, that included other care agencies, day care provision, support to consider other care homes and liaising with ACS. A specific example of HoSF support to both Sarah and Samuel, was their liaison with the GP practice in respect of medication to help Sarah's broken sleep, hence reducing distress to Sarah, and sleep deprivation for Samuel.

16.12.21 The chair explored the identification of concerns regarding domestic abuse in a meeting with the HoSF panel representative and their safeguarding lead. It was established that domestic abuse is seen in the wider context of safeguarding and features as part of a comprehensive matrix of mandatory Level 1, 2 and 3 safeguarding training that includes case studies. Notwithstanding, this training, the identification of domestic abuse is based upon the observation of the couple, training and in some senses is instinctive. Any concerns would be raised immediately with a safeguarding lead at HoSF. Upon examination of the needs assessment framework used, under the section, 'social assessment', there is one section that asks whether there are 'any risks', yes or no. One may argue that the absence of a specific

question on DA adds credibility to the notion of systematic invisibility of DA within elderly communities, as outlined in Safelives publication "Safe Later Lives: Older people and domestic abuse" that suggests 'professionals tend to believe that domestic abuse does not occur amongst older people' [64], In discussion, it was agreed that the focus of this binary question may be improved by framing that question in respect of domestic abuse, ensuring the possibility of there being concerns is always recognised.

16.12.22 The case reflection notes suggest the need to include in routine screening questions; "whether the patient and/or carer have a gun licence or secured gun or whether there anything we should know about that could harm/put people at risk from having a licensed gun stored in the house". On discussion with the panel representative, it was not suggested that this is routine, rather in appropriate circumstances such as when working in rural communities.

16.12.23 Notwithstanding the above, domestic abuse was not apparent in any of the dealings with Sarah nor Samuel.

Family Opinion

16.12.24 On considering the engagement with HoSF, it is clear that their son was very concerned about how Samuel was coping and yet on the other hand he appeared reluctant to accept assistance, saying the time was not right. This raised a number of discursive points including Samuel's rationale and thinking and also his state of mind.

16.12.25 On the one hand it seems that the family recognised the burden that Samuel was under, and on the other hand Samuel's stoicism and/or disguised coping with the situation. The IMR author contemplates "The determination of the Victim's Spouse to be as independent as possible may have been increased by a wish to protect the dignity and reputation of the Victim who had held high profile leadership roles in her local community. However, the wish to protect family members from prejudice and indignity because of the impact dementia has, is common to current experience of family members and people with dementia."

16.12.26 This issue is clearly recognised with a number of easily accessible points of reference to the issue such as the Alzheimer's Organisation in Chicago explaining "Stigma and stereotypes are a significant obstacle to well-being and quality of life for those with dementia and their families. Here are some examples of the stigma you may experience; A diagnosis may test friendships. Friends may refuse to believe your diagnosis or withdraw from your life, leaving a feeling of abandonment or isolation; Relationships with family may change; Family members may not want to talk about the disease, perceive you as having little or no quality of life, or may avoid interacting with you; Others may approach your care partner to ask about you rather than asking you directly how you are doing; The reaction of some friends and family to your diagnosis may prevent you from seeking help from others."[65]

16.12.27 The matter of Samuels capacity was explored with HoSF and at no point this ever come into question. Had his capacity been at question, family members could have applied for legal power of attorney for health and welfare or finances. The panel representative has followed this up and confirmed their understanding that no family member had LPA. This question was asked, and it is procedure to retain a copy on file. Also, if a compulsory assessment for treatment under the mental health act were required the next of kin (nearest relative) can be displaced (Section 29) if they are preventing such an assessment/treatment. This circumstance did not apply in this case.

[64] Source: Safe Later Lives - Older people and domestic abuse.pdf (safelives.org.uk) (Accessed January 2021)
[65] Source: https://www.alz.org/help-support/i-have-alz/overcoming-stigma (Accessed July 2020)

16.12.28 The family were however signposted to available options that included, ACS placement respite to support carers, private funding respite in a residential/nursing home, working with ANC.

Summary Analysis in Respect of Keylines of Enquiry

Term 1: Information Sharing

16.12.29 The initial referral was received from the family GP and further information sharing took place at regular monthly meetings with the GPs, palliative care team and district nurses and other health care professionals.

16.12.30 HoSF proactively engaged with ACS and ANC and attempted to co-ordinate a professionals meeting with these agencies and the family. Unfortunately, ACS and ANC could not attend, and it is recognised that this had the potential to undermine the confidence of the family in the system.

16.12.31 HoSF has also made observations around relationships with other agencies and multi-disciplinary meetings, recommending "Regular Spring Centre Multi-Disciplinary Team meetings/North West Herts MDT discussion and documentation for complex cases ensuring the Hospice social work team aware of situation". This is seen as a positive step. This also links with observations made earlier in the report around the using the "HSAB Multidisciplinary Guidance for Complex Cases 2020" and recent complimentary local guidance on scheduled multi-disciplinary team meetings as a vehicle for bringing agencies together to co-ordinate more effectively across statutory and non-statutory partners.

(LO27) Learning Opportunity/Consideration: *To maximise the opportunity for multi-disciplinary working, enabling the sharing of information by knowing who else the client/carer is working with.*
Individual Agency Recommendation refers: - *To build on relationships with Hertfordshire Partnership Trust and ANC to Hospice to build on the links we have, inviting them to the Hospice to explore options for specific dementia support as appropriate"; - "Regular Spring Centre Multi-Disciplinary Team meetings/North West Herts MDT discussion and documentation for complex cases ensuring the Hospice social work team aware of situation.*
+
Response*: Introduction of (a) Hertfordshire Safeguarding Adults Board Multidisciplinary Guidance for Complex Cases 2020 and (b) Recently introduced and scheduled locality- based MDTs*

Term 2: Key line of Enquiry 2-Assessment and diagnosis

16.12.32 At no time was Sarah deemed as at end of life. She did not meet the criteria for placement at the local hospice but was eligible for hospice outpatient service at the start and community specialist support as her condition deteriorated.

16.12.33 Concerns were raised by family as to how Samuel was coping, and it was clarified that the HoSF uses the Cambridge University CNSAT for its carer's assessments in relation to the specialist and palliative care that a patient needs where the carer has capacity. Samuel's capacity never came into question.

16.12.34 On assessing patient and carer safety and wellbeing, it was clarified that in Sarah's case, this related to the risk of falls, wandering, self-care as well as eating and drinking. In Samuels case, considering resilience, ensuring sufficient sleep. They advised, signposted, and attempted to facilitate other care that was available, that included other care agencies, day care provision, support to consider other care homes and liaising with ACS.

16.12.35 Samuel was also signposted for carers assessments by social care, though on reflection, HoSF in their case reflection made a broader observation in relation to carers assessments.

(LO28) Learning Opportunity/Consideration: *To explain the benefits of exploring carers feelings and needs at each review.*
Individual Agency Recommendation refers: *Include a further trigger for the care team to ensure that we have explained why an in-depth exploration of carers feelings and carers needs could be helpful, reiterating this at each review and/or point of change/deterioration.*

16.12.36 On considering risk, HoSF has made a single agency recommendation for routine questions in relation to firearms.

(LO29) Learning Opportunity/Consideration: *To consider merits of routine enquiry regarding firearms.*
Individual Agency Recommendation refers: *Include in our risk assessment routine question about whether patient and/or carers have a gun licence or a secured gun (in line with the licence requirements) as appropriate*

16.12.37 Whilst domestic abuse was not apparent in Sarah and Samuel's relationship it is recognised that in order to avoid the possibility of the systematic invisibility of domestic abuse and the elderly, the needs assessment could be adapted.

(LO30) Learning Opportunity/Consideration: *To minimise the risk of domestic abuse being systematically invisible, by adapting the needs assessment section on social needs to include a question of domestic abuse.*
Recommendation 2: *Hospice pf St Francis to adapt their risk/needs assessment protocols to include a question/prompt on domestic abuse.*

Term 3: Key line of Enquiry 3-Contact and Support from agencies

16.12.39 HoSF have been proactive with their engagement with Samuel and family, with clear evidence of maintaining contact, weekly and sometimes with calls to Samuel and their son on the same day.

16.12.40 They have also engaged with other agencies (ACS and ANC) at regular 'gold standard' meetings and have co-ordinated one family meeting with themselves, and attempted to co-ordinate a multi-disciplinary family meeting, subject to comment at Term 1.

16.12.41 Proactive engagement with agencies, includes the example of working with the GP to ensure sleeping medication for Sarah to alleviate her distress and ensure Samuel was able to get rest overnight.

16.12.42 HoSF had signposted Samuel to a number of agencies able to support him and Sarah. Samuel declined these offers in January 2019 it was recorded that 'Spouse had responded to date that it was not the right time for these services for them'.

16.12.43 There was no evidence of domestic abuse in the agencies dealing with Sarah and Samuel

16.13 Care Home

16.13.1 The care home (CH) is a private enterprise with a number of residences across the UK offering long term accommodation, specialising in provision for those living with a dementia.

16.13.2 The CH were first contacted by Sarah's daughter in October 2018 to make an enquiry about fees, before this progressing to an initial site visit in January 2019. It has been confirmed that the CH had no engagement with any of the other agencies involved in this case before the tragic events.

16.13.3 Contact with CH began slowly in January, with Sarah visiting and speaking to staff and also visiting friends who were also resident. The process of arranging accommodation, involves carrying out an assessment, collecting information of the individuals care needs, from personal care through to mental capacity. The assessment does not ask about domestic abuse, though the panel representative explained that staff receive annual safeguarding training, incorporating recognising domestic abuse. Given that patients are moving into as secure environment, it is arguable that this is proportionate to the CH's need. In Sarah's case, there were no such concerns, an assessment took place in the presence of her daughter only, she was found to be engaging and in a good mood.

16.13.4 A number of different factors were apparent from the chronology, including the family desire to have a particular type of room, the fact that the daughter was due to return to her home abroad, then a request to see if anything could be done more promptly when the daughter had returned abroad as Samuel had difficulty coping and then when the family were notified a room was available, to have it prepared more quickly as the son had to travel abroad.

16.13.5 Following this last request, Sarah and Samuel visited (13th March). Sarah saw a friend she had been visiting weekly and Samuel was upset and feeling guilty. Upon exploration with the panel representative, they did explore other options such as a carer living in with them, but Samuel explained their home was too small. In hindsight another option may have been to offer a room to Samuel too, but this was not explored or asked for.

16.13.6 A further week passed (20th) and when John attended and there were further discussions as to arrangements and signing of contracts for a move in date of 27th March. Samuel was described as upset and crying. The following day, they visited again and took a friend out for a meal without incident.

16.13.7 On considering the sequence of events, prior to the tragic incident, it is arguable that the planned move into the CH, was in itself a trigger event. Having been married on 1st March and lived together for many decades and having cared for Sarah for over a year as her dementia progressed, Samuel was confronted with a massive change to their lives seemingly in a relatively short period of time. However, from a single agency perspective, the chronology demonstrates an agency that is accommodating towards Sarah and Samuel, but also listening to their children.

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Summary Analysis in Respect of Keylines of Enquiry

Term 1: Information Sharing

16.13.8 The CH did not exchange information with other agencies, being reliant on self-referral.

Term 2: Key line of Enquiry 2-Assessment and diagnosis

16.13.9 There was evidence of Samuel being upset at the prospect of his wife moving into the care home. However, this is not deemed unusual and as their involvement with the family was over a short period of time, it was difficult to assess and changes in Samuel's behaviour over time.

16.13.10 Whilst there was no evidence of domestic abuse in the relationship and screening for domestic abuse, the annual safeguarding training incorporating domestic abuse is seen as proportionate to need.

Term 3: Key line of Enquiry 3-Contact and Support from agencies

16.13.11 The care home did not engage with other agencies, there was no overt cause for concern, need to seek further information from agencies or alert them to a concern.

16.14 Hertfordshire Police

16.14.1 Samuel had held a shotgun licence for a number of years and was due for renewal in August 2017. He commenced the process of renewal in May 2017, submitting an application for renewal. In turn, his GP was requested to comment as to whether there was any reason to decline an application. His GP observed there was no medical reason would be of concern, but that no assessment of behavioural or personality disorders had taken place. The licence was subsequently granted.

16.14.2 On examining the renewal process, the question is asked of applicants, “Have you ever received treatment for depression or any other kind of mental health treatment?” In this case Samuel answered yes, “work stress resolved by change of job”. It seems this was over forty years ago and was rightly discounted as relevant.

16.14.3 The matter of reviewing licences outside the application process was discussed with the police and the question posed, “if the police were to learn that the licence holder (either himself) is suffering from dementia or someone they are caring for is suffering from dementia has access to firearms, would this, could this, should this trigger a review of that licence.” The answer was clearly yes and that “any change in the wellbeing of a licensed holder or family member living with/having access at the same address would cause us to risk assess their continued possession” However, upon examination of the firearms renewal form, there does not appear to be any clear opportunity to disclose details about other parties (or partners) who are resident at the address, nor does it clearly highlight any obligation to inform the police of any changes in circumstances for the applicant or other persons living at the same address.

16.14.4 Two matters arise as a result, the obligation of a licence holder to notify the police of changes in circumstances and any potential obligation the GP may have in this regard.

16.14.5 In considering the first point, we have already learned that the GP was aware of Samuels low mood and offered counselling and medication that had been turned down. It was also learned that he had never expressed suicidal ideation, let alone in the last two years of his life when home circumstances were becoming more challenging. It may therefore be argued that the threshold to consider breaching patient confidentiality and alerting the authorities would not have been met.

16.4.6 However, on considering the obligation of a shotgun licence holder to notify the police of changes in circumstances, the panel considered the renewal application process. The process involves completion of a form that includes under Part B, questions in respect of personal health and whether the applicant has received treatment for depression or any other kind of mental health condition. The process makes no reference at all, as to other people that co-habit with the licensee and/or their medical conditions. There is a question as to whether the security of the firearm is shared with another certificate holder.

16.14.7 Whilst trying to avoid hindsight bias, it is arguable that an individual such as Samuel, who was law abiding up until the point of the homicide, may have considering declaring a change in home circumstances, had the application process placed an obligation for him to do so, in much the same way that exists for individuals who hold a driving licence. In Samuel’s case, one could argue that ‘low mood’ wouldn’t be sufficient nor practical. However, it seems to the panel that this merits further exploration, as does the expansion of the application/renewal process to incorporate details of others living at an address where firearms are stored.

(LO31) Learning Opportunity/Consideration: *To adapt the firearms application/renewal process to place an obligation on licence holders to (a) report changes in their personal medical and mental health and (b) ensure the process assesses the same for those who live at the same address where firearms are kept.*
Recommendation 5: *The Home Office to consider reviewing firearms/shotgun renewal process to incorporate an obligation to report changes to their medical and mental health and that of those who cohabit with the licence holder*

16.15 Equality and Diversity:

16.15.1 The Review Panel identified Sex, Disability and Age as Protected Characteristics requiring specific consideration for this case.

Sex

16.15.2 Sex is recognised as a risk factor in domestic violence, with women being disproportionality affected by domestic abuse and homicide.

Disability

16.15.3 The Human Rights Act 2010 defines disability as "A person has a disability if she or he has a physical or mental impairment which has a substantial and long-term adverse effect on that person's ability to carry out normal day-to-day activities". [66]. Sarah met this definition.

16.15.3 As described at 16.3.8, there are a number of studies that describe the increased probability of people with dementia suffering from domestic abuse and women with mental health problems being more likely to experience domestic abuse. In a recent analysis of DHRs by Standing Together, it was also found that "Mental Health was recorded as the second most common health related theme in DHR reports" and "Mental Health problems may increase vulnerability to inter-personal violence or develop as a consequence of it"[67] The same report observed "disabled survivors face complex and additional barriers when accessing support, especially when their abuser is their carer" and "caring situations should be considered carefully in relation to the pressures that cares face but also how such contexts facilitate abuse"

Age

16.15.4 As described at 11.5 the subject of systematic invisibility of domestic abuse in the elderly is subject to a report by Safelives. The potential for societal ageism is also reflected by the fact that the Crime Survey for England and Wales excludes adults aged over 59 and yet a Home Office analysis of domestic homicides showed that 13% of homicide victims were aged over 75, versus 9% of the actual population.

16.15.5 Whilst, the panel has not identified a pattern of domestic abuse within Sarah and Samuels relationship, the panel recognises the challenges that confront those who do experience domestic abuse who have any one of the three protected characteristics above. The panel also acknowledge that in Sarah's case she was not asked about abuse, nor did it feature as part of any routine questionnaire on assessing need into any service. It could be argued that the overlap of these social identities, heightens the risks of domestic abuse for the individual and it is therefore imperative that agencies recognise and take steps to address the challenge.

[66] Source : https://www.equalityhumanrights.com/en/equality-act/protected-characteristics#disability (Accessed December 2019)
[67] Source: STADV_DHR_Report_Final.pdf (squarespace.com) (Accessed January 2021)

Furthermore, considering the Equalities Act, it places a duty on public authorities to; remove or reduce disadvantages suffered by people because of a protected characteristic; meet the needs of people with protected characteristics; encourage people with protected characteristics to participate in public life and other activities[68]. In these circumstances one may argue a greater burden is therefore placed on authorities to be alert to and ask about domestic abuse in their dealings with such individuals.

16.15.6 A number of individual learning opportunities and recommendations have been identified during discourse and within individual IMR's in respect of routinely asking about domestic abuse and/or including these within local induction to service procedures.

17. CONCLUSIONS AND LESSONS LEARNED

17.1 Conclusions

17.1.1 The chair and panel are mindful of 'Hindsight Bias', highlighting what might have been done differently and avoiding the 'counsel of perfection'. This review panel has attempted to view as broadly as possible what happened, to understand the circumstances of Sarah and Samuel's lives, to help explain the circumstances of their deaths. The panel has also carefully considered the views of available family and friends to shine a light on the broader circumstances of their lives.

17.1.2 Sarah was a loving wife and mother. She was a loyal friend, leading a successful career in public service who sought to help others, including those who were approaching the end of their lives. The deaths of Sarah and Samuel were a tragedy, affecting family and friends deeply, whose own conclusions were of a couple who could not be without each other.

17.1.3 Sarah and Samuel had been married for over 50 years, having been together since school. Both had enjoyed successful careers and a lasting impression from friends and consideration of the facts is that of Samuel being a devoted husband and of a couple who were inseparable. It is apparent that Sarah had possessed a particular strength of character and that Samuel was a very proud and independent man finding it difficult to accept help, save from his children.

17.1.4 It was clear to the panel that Samuel found his caring responsibilities difficult to manage, whilst also having the burden of his own health problems. There were a number of reports as to how stressed he was and that he was at risk of carer's burden. However, no-one had any concerns that domestic violence and abuse was ever an issue, nor is there any evidence of it ever having been an issue or did anyone imagine that a homicide might be the outcome.

17.1.5 Whilst recognising that mental health is a risk indicator for domestic homicide and Samuel had been described as having low mood and stressed, in the months before the tragedy, engagement with agencies had been comparatively limited, with no references to stress, anxiety or low mood. He never expressed suicidal ideation during the relevant period or before.

17.1.6 The lack of any relevant history of domestic abuse or forensic history has been a challenge for the panel, and one may argue the homicide as being 'out of the blue'. However, there was a journey to the final act including the deterioration in Sarah's condition, the impact of caring responsibilities on Samuel's state of mind and the apparent frustration felt by the family in understanding the system of care and what was on offer free of charge. It is a matter of fact that, on approaching the date of the homicide, they had recently celebrated a golden wedding

[68] Source: https://www.citizensadvice.org.uk/law-and-courts/discrimination/public-sector-equality-duty/what-s-the-public-sector-equality-duty/ (Accessed January 2021)

anniversary, their daughter had returned abroad, their son was due to go abroad for work and a date had been agreed for Sarah to move into a care home. Acknowledging that separation is an established risk factor in domestic homicide, the conflation of all these factors is likely to have had an effect on Samuel's state of mind.

17.1.7 However, it is not suggested that the tragic events were either predictable or preventable but reminds professionals of the potential for such events to occur.

17.2 Lessons to be Learned

17.2.1 This review has benefitted from detailed chronologies, candid IMR's and open conversations with panel representatives and other professionals. This has enabled the identification of a number of 'Learning opportunities/considerations' that are contained within the overall analysis for each agency. The review of this case has shone a light on circumstances, enabling thematic learning described below that resulted in this panel's review recommendations that have built upon individual agency recommendations where necessary.

17.2.2 In the course of this review, the panel found limited academic research and articles that suggesting the potential intersection of various risk factors that were apparent in this case including; - an increased odds of domestic abuse for victims living with dementia; -prevalence of victims living with pre-existing medical conditions indicating that offences may have been committed by individuals who were caregivers to chronically ill spouses; - at the time of the offence, most perpetrators had a mental illness, usually a depressive disorder; - articles suggesting that six out of ten carers had been pushed to breaking point; - separation is a common high risk factor. It is emphasised, this does not imply predictability, after all, the subject of Samuels' mood was not brought up with his GP in the months before the events. The point of learning is for professionals to remain vigilant to the possibility of such extreme events occurring.

Homicide - Suicide

17.2.3 Whilst these events were neither predictable or preventable, it is observed that there is limited research available into cases of homicide-suicide, suggesting a need for further research and/or easy access to other DHR's with similar characteristics to help understand why such events happen and inform future professional practice.

Learning Opportunities Refer: *LO1 refers*

Professional Curiosity and Carer Burden

17.2.4 It was apparent that managing dementia had been challenging for Samuel, having an effect on his health and well-being. As a proud man, he found difficulty accepting help from agencies, masking the reality of the situation to professionals, portraying an image of someone coping, as opposed to what his children observed as someone struggling with his caring responsibilities and at risk of carer's burden. This posed a challenge to professionals, the degree to which the contradictory picture was explored and, why he frequently did not accept help (*16.2.4*), versus an individual's right to decide. The panel examined a number of theories, including Samuel not recognising himself as a carer, but also because he was seeking to protect Sarah from the reality of accepting her diagnosis (*16.9.5*). He was signposted for carers assessments, frequently declining them *(14.2.34,39,63&72)* before one was completed, though the panel learned of missed opportunities to signpost him for these assessments.

17.2.5 Agencies have acknowledged the missed opportunity to try and explore why help was not accepted and a number of individual agency recommendations have been made in this regard. The panel also acknowledged and commend the work of Hertfordshire Safeguarding Adults

Board and the release of a Learning Bulletin on Professional Curiosity in October 2020, and the intention to focus on this work in the summer of 2021. The underlying lesson herein is for professionals to be alert to the potential for a client being at risk of carer's burden, encouraging them to recognise themselves as a care and signpost for carer assessments.

Learning Opportunities Refer: *LO5, LO6 ,LO8,LO9, LO11,LO15,LO18, LO24, LO29*

Systemic Invisibility of Domestic Abuse in Elderly Communities & Routine Enquiry

17.2.6 Whilst there were no concerns raised from the review that domestic abuse had featured during the relationship, Sarah was not asked about feelings of safety and well-being, nor did domestic abuse feature as part of routine screening or 'induction' to a new service. It seemed to the panel that the absence of such curiosity adds weight to the discussion about DA within elderly communities being systemically invisible as commented on by Rebecca Zerk at Aberystwyth University who reported 'a paucity of policy guidance and service provision that caters for the needs of people aged 60 years and over'.[69]

17.2.7 The review also found limited available local information/research on murder-suicide but found references to offences having been committed by caregivers in international studies. The review also noted articles showing, an increased odds of domestic abuse among people with dementia vs those without, and women with mental health being more likely to be abused. These deliberations directly informed recommendations in respect of routine enquiry and agencies adapting practices, such as induction procedures to include routine reference to domestic abuse, thereby helping to reduce the possibility of systemic invisibility of domestic abuse. Many of the agencies have taken action regarding routine enquiry before the final panel meeting. Alzheimer's Society work in this regard will be adopted nationally.

Learning Opportunities Refer: *LO4,LO13,LO19,LO20,LO25, LO27 refer*

Multi-Agency Working – Breadth of Offer, Co-ordination & Family Communication

17.2.8 The panel learned of the breadth of local offer and support available to those living with dementia, some of which was free, and in Sarah's case, much of which had to be paid for, as an assessment of their savings meant they were not entitled to free support. Whilst the breadth of offer is recognised as positive and were aware of other agency involvement, they often worked in isolation, not having the benefit of the full picture or seeking the opportunity to co-ordinate, save for monthly MDT meetings with the GP that were limited in agency representation and an attempt by HoSF to host a professional's meeting where key agencies were unable to attend.

17.2.9 The number of agencies and communication at times became a point of frustration for the family (16.2.6), with comments as to how overwhelmed Samuel felt. Whilst it was recognised as positive that agencies engaged with Samuel and the children, this in itself created its own challenges. This was recognised by ACS who at one point sought to control communication with family and are considering whether appointing a lead family member would be appropriate in similar circumstances.

17.2.10 During the latter stages of the review, the chair was signposted to recent guidance *"Hertfordshire Safeguarding Adults Board Multidisciplinary Guidance for Complex Cases 2020",* that is a guide "for practitioners working with adults outlining the importance of adopting a multi-disciplinary approach to practice, particularly when working with people with complex needs or circumstances". In addition, West Hertfordshire also released recent complimentary

[69] Source: Wydall,S. and Zerk, R, 2017. Domestic abuse and older people; Factors influencing help-seeking. The Journal of Adult Protection, 19(5), pp.247-260

local guidance on scheduled multi-disciplinary team meetings across the four localities that make up West Hertfordshire. These meetings are scheduled and have core membership, which includes social care, GP's, and consultant geriatricians. All agencies in this review are able to refer in to and take part in these MDTs.

17.2.11 The panel agreed that the circumstances of this case were complex, not necessarily by virtue of Sarah living with dementia, but by a combination of a number of factors such as; - the number of agencies working with her; - working and engaging with multiple family members; the contradictory picture portrayed by Samuel versus that portrayed by his family. The panel agreed the HSAB guidance and recently introduced structured approach to MDTs provides a vehicle by which any one of those agencies, statutory or non-statutory could in the future seek to work more effectively together.

17.2.12 It is understood that the HSAB guidance will be subject to review in the future, following recent Safeguarding Adults reviews that are yet to be published. It is suggested that this review is also used to inform the next iteration of the guidance.

Learning Opportunities Refer: *LO16, LO22, LO23, LO26, LO28 refer*

Risk Marker - Separation

17.2.13 There were a number of risk markers present during the months leading up to the homicide, such as risk of carers burden on Samuel. Other factors in the days before the homicide such as recently celebrating a wedding anniversary and family members either shortly returning to live or work abroad will have had an effect on Samuels emotional state. Whilst not suggesting predictability, the impending separation from Sarah (16.1.7 to 11) is considered a core component risk factor in this tragedy, that needs to be shared within the overall learning. It is acknowledged the opportunity to consider the whole situation holistically, may have been improved through improved sharing of information via MDTs noted above.

Family Support - Communication

17.2.14 Samuel was far more comfortable with the support of his children, as opposed to that offered by agencies. One of his children lived abroad and came to the UK for extended periods, whilst the other had his own family and business commitments. Communication with the family presented a number of challenges such as the contradictory picture that his children portrayed versus that which Samuel described. It also seemed that on one hand, he did not accept support whilst his daughter visited from abroad, and on the other hand, his family expected more from 'the system' to help Sarah and Samuel. Whilst working with the family, all of whom had legal power of attorney is recognised as positive, adult care services acknowledged the risk of miscommunication and at a point in time requested professionals to cease email communication. It was therefore acknowledged that whilst it is highly desirable to work with family members, careful thought is needed as to how best to manage communication that avoids misunderstanding, by working with a lead family member.

Continuing Healthcare – Independent Advice

17.2.15 The subject of continuing healthcare became a point of contention to the family, who were rightly proud of Sarah's contribution to the local community, and yet seemed unable to benefit from more help to support their parents. The children had explored the options of free continued healthcare to provide that support based on Sarah having been close to the end of life. The panel explored this, learning that such is the nature of dementia, Sarah had not been determined as having been close to end of life and upon assessment of Sarah and Samuel's estate, they were not entitled to free care. The panel did, however, learn of a missed

opportunity to signpost the family to independent advocacy who may have been able to guide them through the system.

17.2.16 Nevertheless, agencies did try and help the family by signposting them to the variety of local agencies that are able to provide assistance, some of which was free.

Learning Opportunities Refer: *LO21 refers*

Firearms licensing

17.2.17 The review found the firearms licensing renewal process merited reviewing, as the police advised the panel if they were to "learn of any changes in the wellbeing of a licensed holder or family member living with/having access at the same address would cause us to risk assess their continued possession". However, the firearms renewal form neither asks about other people living at the address or places an obligation on the licence holder to report changes in his wellbeing.

17.2.18 It is arguable that an individual such as Samuel, who was law abiding up until the point of the homicide, may have considered declaring a change in home circumstances, had the application process placed a strict obligation for him to do so, in much the same way that exists for individuals who hold a driving licence.

Learning Opportunities Refer: *LO32 refers*

Sarah's Voice – Mental Capacity and Best Interests

17.2.19 It is clear from the accounts of family and a range of professionals that Sarah did not cope well with her diagnosis of dementia. Whilst this also had a profound effect on Samuel, it is possible this had the effect of isolating her as it seemed to the panel that Sarah's voice was absent, with reliance placed upon Samuel and the family to make decisions such as a declining Cognitive Stimulation Therapy (16.6.6), and there being only one occasion during the relevant period that she was spoken to in private. On the one hand this may be understandable as Sarah had not wanted to talk about her diagnosis, finding it upsetting and causing distress, but on the other hand it may be argued this had the effect of disempowering her, taking away her right to self-determination. In recognition agencies have made recommendations in respect of Mental Capacity assessments, best interests' decisions and ensuring that professionals actions are 'person-centred' in accordance with guidelines.

17.2.20 Nevertheless, the absence of Sarah's voice remains an overarching impression, arguably itself a barrier to her having the opportunity to put across her view and an opportune point with which to conclude the learning from this review.

(LO32) Learning Opportunity/Consideration: *To ensure that the overall learning from this case is shared, and that in so doing, the voice of an individual living with dementia remains at the forefront.*
Recommendation 6: *The learning from this review is shared across the partnership, assisting development of practice, and reminding professionals to keep the voice of the person living with dementia at the forefront of their minds.*

17.3 Good Practice

17.3.1 There is a considerable breadth of local support available for those diagnosed with and carers of those diagnosed with dementia.

17.3.2 The local GP practice showed itself to be responsive and agile, visiting Sarah at home as required. The practice also listened to their patients and their rights to be involved in decision making/self-determination.

17.3.3 It is arguable that ACS involvement extended beyond requirements, when dealing with Sarah and Samuel who did not have care and support needs as defined by the Care Act.

17.3.4 The ability for Alzheimer's Society to work with HPFT(EMDASS) in the same office space assists with communication between the two agencies.

17.3.5 Alzheimer's Society production of a webinar on domestic abuse shows commitment to tackling DA for a vulnerable cohort.

17.3.6 Agencies were willing to engage with the wider family, receiving and acting on information and signposting as required. ACS were agile in their communication style, ensuring family abroad were involved in discussions.

17.3.7 Whilst domestic abuse is not subject to routine screening in emergency hospital departments, the deployment of IDVA's demonstrates a commitment to tackling domestic abuse.

17.3.8 HSAB has produced an informative guide to 'Professional Curiosity' that has been circulated across all the agencies within this review and that informs the local training offer across all partner agencies involved with this review.

17.3.9 "HSAB Multidisciplinary Guidance for Complex Cases 2020" is an exemplary and practical guide for practitioners, outlining the importance of adopting a multi-disciplinary approach to practice.

18. RECOMMENDATIONS

18.1 Local Recommendations

18.1.1 The following single agency recommendations were made by agencies. They are also described in an analysis of each agency's involvements.

West Hertfordshire Hospitals NHS Trust

18.1.2 Medical staff need to complete Mental Capacity Assessments and best interest decisions when making decisions on behalf of others that lack capacity.

18.1.3 Staff to explore the 'think family approach.'

18.1.4 All Trust staff should be aware of services within the Trust and externally to recognise and support patients who may be carers.

18.1.5 The safeguarding team will continue to highlight the need for professional curiosity.

Adult Care Services

18.1.5 ACS should be more proactive in supporting service users and their carers who are self-funding to access services more effectively.

18.1.6 Staff to attend all safeguarding training courses both face to face and on I-Learn as well as ongoing refresher courses.

18.1.7 Improve recording on ACSIS, encourage staff to attend “Good Recording” training course already offered by ACS Learning and Development.

18.1.8 Improve awareness of domestic abuse for staff. ACS Learning and Development are in the process of working in partnership with The Hertfordshire Safeguarding Children Partnership, Hertfordshire Safeguarding Adults Board, and the Hertfordshire Domestic Abuse Partnership to assess the levels of training needs within our organisation on key safeguarding priorities to inform future training priorities.

18.1.9 Staff to continue carrying out assessments and care and support planning that are person centred in line with the Care Act.

18.1.10 Ensure staff members attend training in relation to Mental Capacity and Best Interest decisions.

18.1.11 Regular supervision to take place where complex cases can be discussed.

18.1.12 Continue to improve joint working with partnership agencies both statutory and in the voluntary sector.

Carers in Herts

18.1.13 A more regular yearly safeguarding refresher is being planned in order to incorporate it within our annual overall in-house Training and Development programme.

Hertfordshire Community NHS Trust.

18.1.14 A recommendation would be that all staff be aware of the importance of carers needs and to offer a carers assessment. This is a current Key Performance Indicator for patients registered in the East and North CCG area and performance against delivery is being closely monitored.

Crossroads

18.1.15 Review of intake processes to improve oversight. Specifically, all enquiries to be managed and monitored by Client Services Team enabling escalation of local blockages in delivery.

18.1.16 Evaluation of software to facilitate pipeline enquiries.

18.1.17 All waiting list entries to carry a risk and urgency rating (following the system used post assessment).

18.1.18 The organisation has set up a new charitable fund and a volunteer service for welfare calls where staffed support is in short supply.

Alzheimer’s

18.1.19 Deliver Dementia Practitioner workshop as a priority to ensure that staff understand the initial assessment and support planning process. This training was completed for DSW’s in the Herts team.

18.1.20 A further operations service review arranged in 3 months to assess the impact of moving to the computerised records system (CRS) on support plans, initial assessments and in

particular, eligibility and waiting lists. A lot of work has taken place to reduce waiting lists and to prepare staff to the move to CRS, and this would be an opportunity to ensure that the move to recording on CRS reduces these known issues. The review identified good practice in 60% of areas assessed. Remaining areas for improvement were addressed through regular monitoring of service delivery and established quality assurance mechanisms.

18.1.21 The Safeguarding and Quality team review the need for initial contact to be documented in guidance or service specifications in future, as it done for Dementia Connect and Side by Side services. Initial contact is documented as part of CRS practice. Initial contact is now attempted via three phone calls at various times of day, if unsuccessful this is followed by a letter and if no response to the letter the case is closed after 3 weeks if they have not responded to the letter.

18.1.22 Ensure the Safeguarding Incident process clearly states who is responsible for ensuring that actions taken as a result of an audit into a Safeguarding Incident is defined. The Safeguarding Incident process has been reviewed and updated by the Safeguarding & Quality team.

18.1.23 Implement regular catch ups between the local management of services and the Safeguarding and Quality team to ensure actions are not missed and are progressed as required. Monthly meetings are held.

18.1.24 Review if the current prioritisation of the waiting list is adequate and consider rolling out the prioritisation tool used in SbS to all services. Review completed, prioritisation tools retained, and cases are reviewed using the CRS reporting processes.

Hospice of St Francis

18.1.25 The following recommendations arose from an internal review conducted by HoSF and are included for completeness.

18.1.26 Include in our HoSF risk assessment routine question about whether patient and/or carers have a gun licence or a secured gun (in line with the licence requirements) as appropriate e.g., if a person lives on a farm or offers information about a gun on the premises or any other triggers. Also ask whether there anything we should know about that could harm/put people at risk from having a licensed gun stored in the house.

18.1.27 Whilst carers assessment was proactively offered and declined, include a further trigger for the care team to ensure that we have explained why an in-depth exploration of carers feelings and carers needs could be helpful, reiterating this at each review and/or point of change/deterioration.

18.1.28 As part of business planning/service development process to look at activities in our programme of care that are beneficial for people with dementia and whether there are barriers to access and explore other activities that could improve dementia palliative and end of life care and how these might be taken forward.

18.1.29 Review our dementia awareness and as part of planning service development in 2020/21 offer training at varying levels to continue to build competence, using our training tracker and face to face modules.

18.1.30 Review our threshold for requesting a joint home visit (CNS/GP or Hospice Doctor/GP, CNS/Social Worker)

18.1.31 Use our evaluation system before and after training to provide a self-assessment indicator about how staff rate their competence and confidence in care for dementia patient and family

in palliative and end of life care if and when appropriate to our services in 'Spring Centre In Patient Unit' and Community, taking action on the results

18.1.32 To build on relationships with Hertfordshire Partnership Trust and ANC to build on the links we have, inviting them to the Hospice to explore options for specific dementia support as appropriate.

18.1.33 Regular Spring Centre Multi-Disciplinary Team meetings/North West Herts MDT discussion and documentation for complex cases ensuring the Hospice social work team aware of situation.

18.1.34 Published research articles referred to by senior doctor to support case reflection discussion to be circulated.

18.2 Overview Report Recommendations

18.2.1 The Review Panel has made the following recommendations, which are also described in analysis of each agency's involvements. These recommendations form the basis of an action plan that will be overseen by the Dacorum CSP.

Recommendation 1: *The Home Office to consider further research into murder/suicide of cases of a similar profile, to develop an understanding and identify actions to mitigate the risk.*

Recommendation 2: *Agencies (ACS, HPFT-EMDASS, Hertswise, Crossroads, Alzheimer's Society and Hospice pf St Francis) to adapt their risk/needs assessment protocols to include a question/prompt on domestic abuse.*

Recommendation 3: *HPFT (EMDASS) to require proof of legal power of attorney for patients.*

Recommendation 4: *ACS in dealing with complex family dynamics, review whether appointing a lead family member is appropriate.*

Recommendation 5*: The Home Office to consider reviewing firearms/shotgun renewal process to incorporate an obligation to report changes to their medical and mental health and that of those who cohabit with the licence holder.*

Recommendation 6: *The learning from this review is shared across the partnership, assisting development of practice, and reminding professionals to keep the voice of the person living with dementia at the forefront of their minds*

APPENDIX A

Hertfordshire Domestic Homicide Review
Terms of Reference

Scope
This review is commissioned by Hertfordshire Domestic Abuse Partnership (HDAP) in partnership with Dacorum Community Safety Partnership as a result of the death/s of ***Sarah and Samuel on 22nd March 2019.***

The review will focus on events from **22nd March 2017** until their death on **22nd March 2019**.

If it becomes apparent to the independent chair that the timescale in relation to some aspects of the review should be extended this will be discussed with and agreed by the review panel and informed to the chair of the Hertfordshire Domestic Abuse Partnership Board (HDAPB).

It is intended that the results of the review, including the panel's findings and recommendations will be shared with their immediate family.

Purpose
The purpose of the review is specific in relation to patterns of Domestic Abuse and/or Coercive Control, and will:

- Establish how effective agencies were in identifying Samuel and Sarah's; health and social care needs, care, and support needs and in providing support.
- Establish the appropriateness of single and inter-agency responses to both Samuel and Sarah, during the relevant period.
- Establish whether and to what extent the single and inter-agency responses to any concerns about domestic abuse and/or coercive control were effective.
- To establish how well agencies worked together and to identify how inter-agency practice could be strengthened to improve the identification of, and safeguarding of, vulnerable adults where domestic abuse is a feature.
- Identify, on the basis of the evidence available to the review, the need and required actions to improve policy and procedures in Hertfordshire, and more widely.
- State clearly, where apparent, when the death(s) were deemed to be preventable and the rationale behind this.

The Review will exclude consideration of who was culpable for the deaths as this is a matter for the Coroner to determine.

Key Lines of Enquiry

Information: How was information about Samuel and Sarah health and social care needs received and addressed by each agency and how was this information shared between agencies?

Assessments and diagnosis:

- What was the impact of Sarah's mental health and well-being on Samuel's physical and mental health and well-being?
- Were there any recent changes in Samuel and Sarah physical or mental health and well-being that may have affected Samuel's behaviour?
- Was there any evidence that Sarah's condition had an impact on Samuel's mental health?
- Could the physical or mental health and well-being of Sarah or Samuel have compounded any safeguarding concerns or considerations or masked evidence of domestic abuse and/or coercive control? Did this result in specific or increased risk and missed opportunities for agencies to probe and respond effectively?

- Is there any clear information in relation to domestic abuse and/or coercive control and its impact? Were any carer's/agency assessments completed?
- Were any carer's/agency assessments completed on any family member?
- Was there any indication or sign of any cultural perceptions or beliefs that were relevant? Did these bring with them any implications on the relationship and behaviours?
- Were there any barriers to seeking support? What were they? How can these be overcome?

Contact and support from agencies:

- What was the nature and extent of the contact each agency had with Sarah, Samuel, and family?
- What support did they receive and from whom; individually and as a family?
- Were there any indicators or history of domestic abuse and/or coercive control? If so, were these indicators fully realised and how were they responded to? Was the immediate and wider impact of domestic abuse on Sarah fully considered by agencies involved?
- Was there any collaboration and coordination between any agencies in working with Sarah and Samuel individually and as a family? What was the nature of this collaboration and coordination, and which agencies were involved with whom and how? Did agencies work effectively in any collaboration and did services work effectively with those working with the family?
- Were there any issues of intersectionality identified and how were they dealt with by agencies? Did the interventions of agencies demonstrate competent strategies and practice of intersectionality in their responses?
- What lessons can be learnt in respect of domestic abuse and/or coercive control, how it can affect adults, children, and young people and how agencies should respond to any impact?

Any additional information considered relevant: If any additional information becomes available that informs the review this should be discussed and agreed by the independent chair and the review panel. The chair of the HDAPB will be advised of the change.

Roles and Responsibilities
Chair Hertfordshire Domestic Abuse Partnership Board
DCS Paul Maghie

Review Panel

- **Independent Chair and Overview Report Writer**
  Mark Wolski
- **Hertfordshire Constabulary**
  Stephen O'Keeffe, Detective Chief Inspector
- **West Hertfordshire Hospital Trust**
  Dawn Bailey, Named Nurse for Adult Safeguarding
- **Hertfordshire Partnership Foundation NHS Trust**
  Clare Landy,
- **Adult Care Services (to include Social Care Access Service and Adult Care Services Older Peoples Team)**
  Deidre Haynes, Health and Wellbeing Manager
- **Hertfordshire Community NHS Trust**
  Naomi Bignell, Named Nurse Safeguarding Adults
- **Hospice of St Francis**
  Fay Richardson, Director of Care
- **Clinical Commissioning Groups**
  Tracey Cooper, Associate Director for Adult Safeguarding
- **Care Home**
  Diane Delicate, Home Manager

- **Crossroads Care**
  Michael Farrell, Chief Executive
- **Carers in Hertfordshire**
  Carole Whittle, Health and Wellbeing Manager
- **Dementia UK**
  Victoria Lyons, Senior Consultant
- **Hertfordshire County Council (local authority)**
  Katie Dawtry, DA Development Manager
- **Refuge (Specialist Domestic Violence Advocacy Service)**
  Martina Palmer,
- **Dacorum Community Safety Partnership**
  Sue Warren,

Review Panel Independent Chair
Mark Wolski
Foundry Risk Management

Contact with Family
All contact with family members will be made in consultation with the assistance of the Homicide Support Service or Family Liaison as appropriate.

Liaison with the Home Office
Katie Dawtry
DA Development Manager
Hertfordshire County Council

Appointment of Overview Report Writer
Mark Wolski
Foundry Risk Management

Overview Report Writer
Subject to timely receipt of IMRs and chronologies, to produce a draft overview report by 13th April 2019 and a final report by 13th May 2019:

- Summarises concisely the relevant chronology of events including the actions of all the involved agencies.
- Analyses and comments on the appropriateness of actions taken.
- Makes recommendations which, if implemented, will better safeguard vulnerable adults where domestic violence is a feature.

Signed: Electronic signature

Name
Chair Domestic Homicide Review Panel

Date

APPENDIX B - Independence statement

Chair of Panel

Mark Wolski was appointed by Somerset Community Safety Partnership as Independent Chair of the DVHR Panel and is the author of the report.
He is a former Metropolitan police officer with 30 years operational service, retiring in February 2016. He served mainly as a uniformed officer, holding the role as Deputy Borough Commander at the Boroughs of Haringey, Harrow and at the Specialist Operations command of Aviation Security.
During his service he gained significant experience leading the response to Domestic Abuse, Public Protection and Safeguarding
Mark has subsequently acted as a consultant in the field of Community Safety, Independent Chair of a Marac Steering Group and as a DHR chair/co-chair.
During and since his MPS service he has had no personal or operational involvement with Dacorum Community Safety Partnership.

APPENDIX C – Dissemination List

Name	Agency	Position/ Title
Mary Moroney	Hertfordshire County Council	Safeguarding Boards Manager
Kay Lancaster	Hertfordshire Constabulary	Head of Serious Crime and Safeguarding Command and Chair of the Hertfordshire Domestic Abuse Partnership Board
Jo Fisher	Hertfordshire County Council, Children's Services	Director of Children's Services
Chris Brace	Office of the Police and Crime Commissioner	Chief Executive
Kevin McGetrick	Office of the Police and Crime Commissioner	Head of Commissioning and Victim Services
Amanda McIntyre	For Baby's Sake Trust	(Domestic Abuse Executive Board's voluntary sector representative)
Jane Kinniburgh	Herts Valleys Clinical Commissioning Group	Director of Nursing and Quality
Jacky Vincent	Hertfordshire Partnership University NHS Foundation Trust	Director of Nursing
Joanne Doggett	Hertfordshire County Council, Public Health	
Chris Badger	Hertfordshire County Council, Adult Care Services	Director of Adult Care Services
Neeve Bishop	National Probation Service	Head of Hertfordshire NPS
Mary Emson	East & North Herts CCG and Herts Valleys CCG	Designated Nurse for Safeguarding Children
Claire Hamilton	Dacorum Community Safety Partnership	Chair
Sarah Browne	Hertfordshire Community NHS Trust	Director of Nursing and Quality

Appendix D – One Page Summary

1. Domestic Homicide Review

Dacorum Community Safety Partnership commissioned this DHR following the homicide of Sarah by her husband Samuel. He took his own life immediately after.

2. Case Summary

Sarah was diagnosed with dementia. Her primary carer was her husband Samuel of over 60 years. Her condition deteriorated over a period of two years, and whilst engaged with multiple agencies, he frequently denied assistance as she found it difficult to accept her diagnosis. He was a licensed shotgun holder and two days before her planned move into a private care home, he shot her and then himself, leaving two notes, one for the police and one for his family.

3. The Facts – an overview

Diagnosed with dementia were well known to their GP, frequently attending together and Samuel for his own health concerns.
Proudly independent, in the first-year post diagnosis, he looked after his wife, taking more and more of the day-to-day household tasks and over time undertaking more of the personal care required for Sarah.
She was referred for a full diagnostic assessment and signposted to other community organisations for help and support. Following diagnosis, the final year of their life was typified by multiple-agency contact with Samuel and his two children.
It was apparent that he frequently portrayed himself to professionals as coping, whereas his children described him as struggling with the burden of care.
Agencies did report that he was at risk of carers burden, though he turned down agency support, preferring to rely on the support of the children. He did report 'low mood' but declined any medicinal support and at no time disclosed suicidal ideation.
At some points in the two years, they were engaged with ten agencies and Samuel reportedly found this confusing.
Whilst assessed as not having care and support needs, adult care services were involved, working with the children, and advising on continued healthcare as well as Similarly, whilst not being determined as at being at end of life, the Hospice of St Francis and other agencies worked to try and support them.
There were limited attempts at multi-agency co-ordination, and one attempt by HoSF to host an MDT meeting.
At no point were there concerns of there being domestic abuse in the relationship.

4. Learning Points

The review found limited available research into homicide-suicide cases and welcomes the planned repository of all DHRs to share learning.
The review showed opportunities for improved professional curiosity to explore carer burden, though acknowledges the work of the Hertfordshire Safeguarding Adults Board and continued focus on professional curiosity.
The review found that omission of screening for domestic abuse added weight to the debate that domestic abuse within elderly communities is systemically invisible.
The review identified opportunities for improved co-ordination and communication across agencies working with families living with dementia, though acknowledges subsequent developments such as Hertfordshire Safeguarding Adults Board Multidisciplinary Guidance for Complex Cases.
The review found that there were a number of risk markers present and the conflation of these with imminent separation will have had a significant effect on the perpetrator.
Recognising that agencies engaged in a positive manner with all immediate family members, it was acknowledged communication requires careful handling to avoid confusion.
The review found that managing expectation around the constraints of continuing healthcare provision require careful handling.
The review identified opportunities for a more robust firearms renewal process.
The review found that Sarah's voice seemed to be absent, with great reliance on Samuel and children, though acknowledges her reticence to talk about her diagnosis.

5. Recommendations

Recommendation 1: The Home Office to consider further research into murder/suicide of cases of a similar profile, to develop an understanding and identify actions to mitigate the risk.
Recommendation 2: Agencies (ACS, HPFT-EMDASS, Hertswise, Crossroads, Alzheimer's Society and Hospice pf St Francis) to adapt their risk/needs assessment protocols to include a question/prompt on domestic abuse.
Recommendation 3: HPFT (EMDASS) to require proof of legal power of attorney for patients.
Recommendation 4: ACS in dealing with complex family dynamics, review whether appointing a lead family member is appropriate.
Recommendation 5: The Home Office to consider reviewing firearms/shotgun renewal process to incorporate an obligation to report changes to their medical and mental health and that of those who cohabit with the licence holder.
Recommendation 6: The learning from this review is shared across the partnership, assisting development of practice, and reminding professionals to keep the voice of the person living with dementia at the forefront of their minds.

6. Links and further information

To be inserted post publication.