



## Camden Safeguarding Adults Partnership Board

# Serious Case Review in respect of ZZ

Died 10<sup>th</sup> June 2014, aged 79 years

SCR Panel Chair: *Marian Harrington*  
Overview Report Author: *Jane Lawson*  
Date: *July 2015*



# CAMDEN SAFEGUARDING ADULTS PARTNERSHIP BOARD

## SERIOUS CASE REVIEW IN RESPECT OF ZZ JULY 2015

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### **Acknowledgements**

Thank you to all those who have contributed to this review including: ZZ's family and neighbours for the time they gave to enabling the panel to obtain a picture of ZZ as a person; the SCR panel for contributing openly and fully to this review with a commitment to identifying learning and taking positive action; and professionals who supported the process of this review.

## 1. INTRODUCTION

- 1.1. ZZ<sup>1</sup> was a 79 year old woman who died on 10<sup>th</sup> June 2014 in circumstances that give rise to concerns about the way that local professionals and agencies work together to safeguard adults at risk. The cause of ZZ's death was multiple organ failure and septicaemia.
- 1.2. Those concerns led to a decision, in line with the Camden Safeguarding Adults Partnership Board (SAPB) Serious Case Review (SCR) protocol, to undertake a SCR in respect of ZZ.
- 1.3. A SCR is not an inquiry into how an individual died or who is culpable. It is not intended to reinvestigate the case or apportion blame, but to learn lessons and make recommendations to improve practice, procedures and systems and ultimately to improve the safeguarding and wellbeing of adults at risk in the future.
- 1.4. All agencies will have their own internal/ statutory review procedures to investigate serious incidents. Agencies may also have their own mechanisms for reflective practice. This SCR is not intended to duplicate or replace these.

## 2. BACKGROUND – the circumstances that led to an SCR being undertaken

- 2.1. ZZ was in receipt of a care package consisting of three periods of care each day commissioned by Camden Council Adult Social Care (ASC) from Plan Care (PC) home care agency. The care package included: personal care, support to prepare food and domestic tasks. ZZ's nephew also visited around three times per week, bringing shopping.
- 2.2. On the morning of 9<sup>th</sup> June 2014, ZZ's two carers from PC contacted her GP to report that ZZ was poorly – disorientated and weak, refusing to eat any food and barely drinking. London Ambulance Service (LAS) was called out, but ZZ refused to go to hospital and was deemed by LAS at this point to have capacity. The GP was called to ZZ's home, and on arrival found ZZ to be incoherent, emaciated, unkempt and with grade 4 pressure ulcers on her sacrum and elbow and elsewhere on her body. When the GP asked paramedics to move ZZ from the sofa, the large stained dent suggested that she had been lying in the same position for a long time. The GP determined that at this point ZZ did not have capacity and urgent hospitalisation was in her best interests.
- 2.3. At 14:22 on 9<sup>th</sup> June 2014 ZZ was admitted to University College London Hospital. The discharge nurses noted she was in the foetal position, with severe muscle wastage (contracture) and extremely malnourished. They diagnosed 13 pressure ulcers at various sites across her body including hands, feet, chest, sacrum and legs. Nine of these were grade four and bones/ tissue were visible in places. University College London Hospital raised a safeguarding alert, and a safeguarding investigation was initiated. ZZ's nephew was present on the ward. A safeguarding alert was also raised by LAS and by the GP.

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<sup>1</sup> ZZ is used throughout this report in respect of the female subject of this SCR. This is in order to preserve anonymity.

- 2.4. At 18:20 on the evening of 9<sup>th</sup> June 2014, ZZ was admitted to intensive care, and passed away on the afternoon of 10<sup>th</sup> June 2014. A post mortem found that ZZ died of multiple organ failure due to septicaemia, caused by infected ulcers. On 11<sup>th</sup> June 2014, the case was referred to the police under the category of wilful neglect.
- 2.5. These concerns led on 14<sup>th</sup> August 2014 to a decision to undertake a SCR in respect of ZZ. This decision was taken in line with the Camden SAPB SCR protocol. The rationale for undertaking this SCR is included in the SCR protocol which states that “Camden SAPB has responsibility for conducting a SCR when there are concerns about the way inter-agency working to safeguard an adult(s) at risk may have been a factor in the death of an adult(s) at risk ...where abuse or neglect is known or suspected to be a factor in their death.”

### 3. TERMS OF REFERENCE AND METHODOLOGY

- 3.1. This SCR was commissioned by the independent chair of Camden SAPB and commenced on 16<sup>th</sup> October 2014 when the panel met to agree terms of reference for this SCR.
- 3.2. An independent chair, an independent overview report author and panel membership for this SCR was determined as follows:

**Table 1:**

<b>Name</b>	<b>Organisation</b>
Marian Harrington	Independent Chair, Camden SAPB and SCR panel
Jane Lawson	Independent Overview Report Author
Jo Adams	Camden Council, Housing Management
Stephan Bruschi	NHS England
Jacquie Burrow	Metropolitan Police Service, Camden
Andy Chambers	Metropolitan Police Service, Camden
Mary Clifton	Camden Council, Adult Social Care
Amanda Haldenby	Metropolitan Police Service, Camden
Julian Hutchings	Plan Care
Betsey Lau-Robinson	University College London Hospital
Neeshma Shah	Camden Clinical Commissioning Group
Patrick Brooks	London Ambulance Service
Tim Rising	Camden Council, Procurement
Ros Alexander	Camden Council, Legal
Sophie Hutchings	Camden Council, Communications
Sarah Lui	Camden Council – SAPB business management
Reshma Upadhyaya	Camden Council – minutes

3.3. The SCR panel (and by extension, Individual Management Review (IMR) authors) agreed to consider and reflect on the following **specific areas of enquiry**:

- **Which agencies were in contact** with ZZ from 1<sup>st</sup> December 2011 until her death on 10<sup>th</sup> June 2014 (and any relevant contact prior to 1<sup>st</sup> December 2011), and the nature of each agency's involvement. *[The review start date of 1<sup>st</sup> December 2011 was identified as social care input began when P2 went into University College London Hospital at this time].*
- **What information was available**, and to whom, in relation to the care being provided to and welfare of ZZ, from 1<sup>st</sup> December 2011 until her death on 10<sup>th</sup> June 2014 – including any reports of concerns in relation to the care or welfare of ZZ. Where an agency had had significant input, contact with or intervention for ZZ prior to 1<sup>st</sup> December 2011, agencies were free to include additional significant information and/ or serious issues in the IMR and/ or chronology that was relevant to the remit of the SCR as background and contextual information.
- **What review, monitoring and quality assurance** mechanisms each agency had in place, and the robustness of these, to monitor the care being provided to and welfare of ZZ and respond to any deterioration, change in circumstances (e.g. death of partner), increased risk or concerns.
- How well agencies worked together to **recognise, identify and respond** to issues of:
  - a. Deterioration
  - b. Non-engagement/ refusal of services
  - c. Mental capacity
  - d. Wider health and care needs (e.g. medication, suitability of housing, occupational therapy etc.)
  - e. Anything that ZZ considered important in nature.
- Whether issues – particularly of non-engagement, capacity or deterioration – **were escalated** to senior management or other organisations and professionals, if appropriate, and in a timely manner.
- The extent and adequacy of:
  - a. Identification of key opportunities for assessment and intervention
  - b. Risk assessments and other relevant assessments undertaken by each agency
  - c. Critical decision-making and appropriateness of services offered/ provided in light of assessments
  - d. Timeliness and effectiveness of actions and interventions
  - e. Ongoing care planning and reviews
  - f. Support to ZZ and her family in understanding key issues and how to contact agencies
  - g. Involvement of ZZ and her family in decision-making.
- Whether the work undertaken by services in this case was consistent with each agency's professional standards and relevant **policies, procedures, protocols and clinical governance** (particularly those relating to safeguarding, mental capacity and non-engagement).

- Whether an improvement in any of the following might have led to a different outcome for ZZ:
  - a. **Communication** within and between agencies
  - b. **Information sharing** within and between agencies, and with family members
  - c. **Review and monitoring** of care by agencies and response to any changing needs
  - d. **Commissioning and procurement** arrangements and practice for contracting care services.
- Whether practices by all agencies were sensitive to the gender, age, disability, ethnic, cultural, linguistic and religious identity of ZZ and whether any additional needs were explored, shared appropriately and recorded.
- Whether the impact of **organisational change** over the period covered by the review impacted in any way on agencies' ability to respond effectively.
- **Whether there are lessons to be learned** about how individuals and agencies work together to safeguard adults at risk – identify what those lessons are, and recommend how they are to be acted upon and what is expected to change as a result. Examples of good practice which can be adopted across agencies, should be highlighted in IMRs and through the SCR process, as well any gaps in compliance or adequacy of inter-agency policies, procedures or protocols.

3.4. The **methodology** for undertaking this SCR was as follows:

3.4.1. An IMR and chronology was requested from each of the following organisations.

- Camden Council Adult Social Care and Joint Commissioning
- Camden Council Housing
- Camden Council Procurement
- Care Quality Commission
- GP practice
- London Ambulance Service
- Metropolitan Police Service – Camden
- Plan Care
- University College London Hospitals NHS Foundation Trust

An integrated chronology was compiled using the single agency chronologies. The period under scrutiny was from 1<sup>st</sup> December 2011 to the date of death of ZZ.

3.4.2. Agencies submitted in support of their IMR and chronology the following evidence where appropriate and available:

- Key assessments
- Reports
- Reviews of patients/ service users/ services
- Links to relevant policies and guidance
- Statements (e.g. some of those taken from staff and/ or by the police)
- Details of expectations and requirements as outlined in service specifications, contracts etc.

- 3.4.3. These documents were presented by the IMR authors to a SCR panel discussion on 19<sup>th</sup> December 2014.
- 3.4.4. An independent overview report writer was commissioned to work with the SCR panel to prepare a report informed by their work. The independent person provided external objectivity to the process.
- 3.4.5. The panel agreed to involve in this review key family members of the adult at risk, as well as other people who may have been able to contribute to the review process. The following met or had a conversation with the panel chair and/ or the independent overview report author:
- A sister of ZZ (S1)
  - The nephew of ZZ (N1)
  - A neighbour (NB1)
  - A further neighbour (NB2) declined involvement but information had already been contributed by them via the Police.
  - A brother in law (B1) also contributed information through the police interviews.
- 3.4.6. The overview report collates and analyses the information contained in the IMRs and any other reports/ information presented to the SCR panel with reference to relevant research/guidance. It highlights lessons learned and draws overall conclusions in terms of key issues for the safeguarding partnership. It makes recommendations on what actions the safeguarding partnership should take following the SCR.
- 3.5. The emphasis in this review is on the lessons and implications for *multi-agency* working.
- 3.6. Individual Management Reports (IMRs) have been prepared by all agencies involved with ZZ and deal in detail with the actions required within each individual agency. Camden SAPB will provide a scrutiny role in relation to single agency action plans but individual actions/ recommendations have only be included in the SCR overview report recommendations where they:
- have significant implications across agencies
  - underline highly pertinent matters which may have received tepid attention in the IMR recommendations – and Camden SAPB needs to be alert to them.
- 3.7. The final report was taken to Camden SAPB on 15<sup>th</sup> July 2015.

## **4. ZZ: THE PERSON**

- 4.1. ZZ was born in Ireland on 5<sup>th</sup> August 1934. She died on 10<sup>th</sup> June 2014.
- 4.2. Aged about 17 years, ZZ visited a sister living in London and decided to stay. She was one of four sisters. One sister (the mother of N1 and wife of B1) died suddenly aged 47 years. ZZ worked in London in the printing department at the football pools office. She and two of her sisters all worked there together (including S1).
- 4.3. ZZ married in the 1950s but the marriage didn't last. There were no children.

- 4.4. In 1974, ZZ first moved to the address where she lived until her death. ZZ lived there with two different partners: one (P1) from 1974 until his death in 1981; and then with a subsequent partner (P2) until his death on 22<sup>nd</sup> May 2013.
- 4.5. It is recorded that ZZ suffered with agoraphobia. By the time of her death she had not left her home for around 25 to 30 years. Prior to this it is known that she would go out to the coffee shop or to the pub. She had not been upstairs for around 20 years by the time of her death. ZZ lived in a maisonette consisting of a kitchen and living room downstairs and two bedrooms and a bathroom upstairs.
- 4.6. The GP practice IMR indicates that ZZ “suffered from a number of longstanding chronic medical conditions including: hypothyroidism, hypertension, depression. These were treated with medication. The conditions required supervision and review rather than active management with intervention. The medical history indicates that the conditions were stable and well-controlled.”
- 4.7. From conversations with family and a neighbour, and from transcripts of several police interviews with those who knew ZZ, there are a number of characteristics of ZZ and impressions of her lifestyle that emerge as consistent:
  - 4.7.1. ZZ’s family kept in regular contact with her. Her sister (S1) phoned her once or twice each week and said that their older sister also phoned her regularly. ZZ’s brother-in-law (B1), S1 said, called ZZ about once a month and visited every six months. Except when B1’s wife/ N1’s mother/ ZZ’s sister died, ZZ never visited B1. S1 also visited twice each year from Ireland. Since ZZ’s partner (P2) died in 2013 her nephew (N1) visited at the weekend and on a Tuesday or Wednesday. He supported her by getting shopping and collecting pension amongst other things.
  - 4.7.2. In 2011 when P2 was admitted to hospital, according to her nephew, ZZ rang N1’s father and asked him to move in with her because she didn’t like being on her own. Then she asked N1 the same question. N1 said that she had depended on P2 and they had been together since around 1983/84. They (N1 and B1) declined to live with her but called the hospital to say ZZ was dependent on P2 and required care and support. Neighbours (NB2) had been looking after ZZ until this point. A care agency (PC) then took over responsibility for day to day care with some input from N1 with shopping and finances.
  - 4.7.3. The two long term partners (P1 and P2) who lived with ZZ following the breakup of her marriage are reported to have done everything for her. ZZ’s nephew said that ZZ had the “upper hand” with her partner (P2). She was resistant, he said, to N1 calling an ambulance when P2 was ill and needed it. P2 asked ZZ’s nephew to call for the ambulance because he didn’t want to go against ZZ’s wishes. N1 said that she didn’t want an ambulance for him, any more than she wanted one for herself. ZZ was very close to P2 and even gave up smoking because of the risks associated with oxygen that P2 required on coming out of hospital in 2013. This appears to have been a significant gesture. She began smoking again after he died.
  - 4.7.4. ZZ was reticent about seeing a doctor or going into hospital. ZZ would suffer rather than tell anyone and didn’t like to make a fuss or worry people. She is



described as a “private” person. She wouldn’t want to get anyone into trouble. She came, her nephew said, from a time when you didn’t complain. He said that in respect of any health issues his aunt never told anyone but “dealt with it herself”. He advised that she had stopped taking her tablets because she said she felt better. Her neighbour (NB2) said that she was afraid of doctors and hospitals and never complained of pain. S1 said that her older sister had told her that ZZ had said “if I were sick I wouldn’t tell [S1] because I wouldn’t want to worry her”.

- 4.7.5. Equally she had been reluctant to have carers coming in but her nephew said that she did get on with them and liked them. Her nephew said that she never complained about her carers, maybe because they just did as she asked. ZZ, he said, liked routine and didn't like it when her regular carers went on holiday or even if they were late.
- 4.7.6. As outlined above ZZ is reported to have suffered with agoraphobia. Her brother in law reported to the police that he had not seen her move from her left side lying on the sofa in 18 months. Her nephew reported that she had not been out for 30 years and had been on the sofa for as long as he could remember. Her neighbour described ZZ as being “part of the sofa”. Her neighbour (NB1) said that ZZ had a fear of going out and was never encouraged to overcome it. The neighbour said of this fear of going out, “She just slowly fell into it”. This neighbour (NB1) said that P2 had “brought the outside in to her.” It was said, in the context of the agoraphobia, that ZZ didn’t go to P2’s funeral. ZZ’s nephew reflected that, given that ZZ had not been out for 30 years, mixing would have been a problem for example in a care home setting.
- 4.7.7. ZZ is described as having two pleasures in life: cigarettes and a drink. Following the death of P2 she did not even watch TV but just lay on the sofa doing nothing. She had a budgie in a cage in her sitting room.
- 4.7.8. S1 said that mentally ZZ was one hundred percent OK. She was very able to chat. Her nephew said that he sometimes felt ZZ had mental health issues. She seemed very depressed. She was quite shaky and a chain smoker. A neighbour, NB2, said in a police interview that the social worker had said to him that “you can’t force people to be washed and do what you want to do as she had mental capacity.”
- 4.7.9. A number of accounts refer to ZZ’s flat not being very clean and to the smell of urine from the commode. The police interview with B1 records him as saying that 2 to 3 weeks before she died she looked pale and gaunt and her arms were skinny and her hair matted. On most recent visits he didn’t want to give her a kiss because of her poor personal hygiene. NB1 and S1 described her at the end of her life as being thin and frail.

## **5. CASE OUTLINE**

- 5.1. The focus of this SCR is on the period 1<sup>st</sup> December 2011 until the death of ZZ on 10<sup>th</sup> June 2014. This case outline is taken from the combined chronologies submitted by those agencies involved with ZZ and other supplementary information provided to the review. Comments (mainly for clarification) of the report author are

set out in brackets and *[in italics]*. An exhaustive chronology has been made available to the panel. This section sets out excerpts and a substantial part of this chronology for reference and as background to the following analysis in section 6.

- 5.2. The Housing Department chronology submitted to this review contained helpful background to this period (prior to 1<sup>st</sup> December 2011) as follows.
  - 5.2.1. The Housing Department was made aware in 1982 by Social Services of a referral from ZZ's GP stating that she was agoraphobic and unable to get out and seek help with finances. At this point ZZ was described as "very anxious and socially isolated".
  - 5.2.2. Housing Department records for 1984 show a GP medical report: "GP had referred ZZ to a consultant psychiatrist in 1983 "because her neurotic symptoms had become so pronounced". He said she was "a vulnerable, anxiety prone woman who had become lonely and probably depressed ... by ... sudden loss of companionship..." He notes follow up appointments with the psychiatrist had not been kept." Housing Department records show that P1 had died in 1981.
  - 5.2.3. Rent arrears were an issue throughout the 1980s. In 1993 remaining arrears were written off by the Housing Department in part because of concern about the impact of payments on ZZ. At this time the request to write off the arrears noted that ZZ suffered from severe anaemia, ulcers, agoraphobia and was "a very nervous person". There had been substantial contact particularly regarding arrears in the 1980s and 1990s. There was little contact with Housing then once ZZ's second partner, P2, was on the scene until 2010 when there were issues regarding improvements to the accommodation.

## **2011**

- 5.3. In December 2011 ongoing contact with ASC and a care agency (PC) commenced because ZZ's partner (P2) was in hospital. On 1<sup>st</sup> December P2 expressed concern about his "bedbound partner" (ZZ). A nurse contacted ASC who telephoned ZZ and an emergency home visit was made by ASC. Neighbours (NB2) had been supporting ZZ but were unable to continue with this. They reported that ZZ had fallen within the last two weeks. ZZ said that she could wash herself down but that her partner did all the cooking and cleaning. The next day an emergency package of care was agreed and the keys were given to the care agency (PC) on 5<sup>th</sup> December (ZZ said that she was unable to answer the door). The social worker (SW1) identified ZZ as requiring support with "Activities of Daily Living". He recorded that the neighbours (NB2) had been doing shopping, cooking and emptying the commode. SW1 discussed with the duty senior practitioner and agreed a reablement home care package. It was recorded that ZZ had not had much to eat in the last three days with only a sandwich a day, and that she was at high risk of falls and alcohol abuse was mentioned. ZZ was agreeable to accepting care.
- 5.4. The referral to the care agency, PC, from SW1 specified at this point the following outcomes should be met for ZZ:
  - "To provide support and assistance with personal care and domestic tasks while carer [P2] is in hospital."
  - "To ensure that ZZ's personal hygiene is maintained."
  - "To ensure adequate nutrition intake as ZZ is unable to prepare any meal."

It also noted: “ZZ suffers from nervous anxiety which makes her generally shaky. She said that she has been housebound for years as she doesn’t like open spaces. ZZ has poor mobility; can only mobilise within the lower floor of her flat. ZZ’s neighbour [NB2] assists with finances and shopping until her husband gets out of hospital.” [*This reference to her husband should be to her partner, P2*]

- 5.5. The service requested was for three visits per day, seven days per week as follows:

0900 for one hour.

“Carers to assist ZZ to have a strip wash, to get dressed, empty the commode and prepare breakfast. If ZZ refuses to have breakfast carers to prepare a snack and leave it on the table so she can have it later on.”

1300 for half an hour.

“Carer to prepare lunch for ZZ as per her instructions and assist with personal care if needed.”

1930 for half an hour (this was increased to 45 minutes from 23<sup>rd</sup> December 2011 – see paragraph 5.9).

“Carer to prepare lunch for ZZ as per her instructions and assist with personal care if needed. If ZZ refuses to have breakfast carers to prepare a snack and leave it on the table so she can have it later on.” [*Reference to breakfast is an error*].

- 5.6. This was confirmed in documentation by a PC field service assistant on 9<sup>th</sup> December. It was noted “Care Worker to support and encourage ZZ to do as much as she can and help when needed.”
- 5.7. At the same time manual handling and medication assessments were carried out by PC. Within these it was noted that:
- “ZZ is house-bound due to poor mobility.”
  - “ZZ sleeps on a sofa in the living room.”
  - “ZZ can’t weight bear and limited upper body strength.”
- ZZ was noted as able to take her own medication.
- 5.8. On 19<sup>th</sup> December SW1 called the GP practice requesting that a GP visit as ZZ had diarrhoea. ZZ declined the visit and agreed to a telephone call the next day. It appears however that on the same day a blood test was taken by a community nurse. The telephone call was made by the GP on the following day and ZZ said that she was better.
- 5.9. On 22<sup>nd</sup> December the first review was conducted by SW1 via a home visit, 17 days after the emergency home care package was put in place. As a result of the visit, it was identified that there was insufficient time in the home care package for the carer to prepare the evening meal, and the evening visit was temporarily increased by 15 minutes until a microwave could be purchased.
- 5.10. This change to the home care package was recorded in the case notes. There is not a formal review document on file. Therefore, it is likely that as for later reviews, ZZ confirmed that the care package was meeting her needs (other than the

evening meal), and that the review did not specifically explore individual risks or outcomes.

- 5.11. The police summary from their interviews in relation to ZZ states that carer 2 records in the daily log on this day “reddish bum due to pressure sore”. This, the police report says, continues to be mentioned through to 15<sup>th</sup> February 2012, which is the last time carer 2 mentions it, saying on this occasion that cream was applied. It was in February 2012 that there is a reference to a call from ZZ to the GP in respect of a “red blotch”.
- 5.12. In December/January issues with the boiler and toilet were referred to the Housing/ complaints department. The issues regarding the boiler continued into 2012.

## **2012**

- 5.13. In January there were ongoing communications chiefly between Housing, the social worker and ZZ relating to boiler/ heating issues and ZZ’s refusal to allow access to her flat for maintenance staff. This was affecting the ability of the Housing Department to deal with heating issues in a neighbouring flat. ZZ refused to have any work done as she could not cope with the dust and noise and refused the offer of a temporary move because she was agoraphobic. The record states that the social worker advised that since “ZZ is mentally fit we should ask for a court order to complete...works”. The Housing Officer however suggested this may cause ZZ distress. In April this issue was still not resolved and P2 was about to be discharged (requiring oxygen 16 hours per day). The Housing Department chronology states that “There is no record of whether the heating system was replaced but there is no further reference to progressing an access order so it is likely that access was arranged after P2 came out of hospital. [Neighbour] sold his flat in July 2012”. A record of supervision of SW1 reference to the housing work to be starting in due course (late April). [*This scenario bears some of the same hallmarks of later issues/ dilemmas regarding self-care, capacity, consent, and impact on self or others*].
- 5.14. In January PC conducted an annual appraisal of a key care worker (carer 1) and a quality monitoring review. It was noted that no change was required to the service and it was working well. ZZ was reported to be very pleased with her regular care worker (carer 1). There was onsite and offsite supervision of carer 1 in May when excellent feedback from service users about carer 1 is recorded. PC’s comment on the chronology states that carer 1 “did not raise any concerns about ZZ”.
- 5.15. In February there is a reference to skin damage (the only reference in the chronologies submitted for this review (but see paragraph 5.11) except right at the end of ZZ’s life). This is in a record of a telephone call that ZZ had with a GP in which she reported a red blotch on her hip. She requested cream and was told to contact the practice if it was not healing. There was no further reference to this and no further recorded action.
- 5.16. On 11<sup>th</sup> April SW1 visited ZZ and recorded: “I visited ZZ this morning to find out if she had any news about her partner’s discharge and if there were any problems with the carers... ZZ stated that her needs are adequately met with the current care package”.

5.17. On 16<sup>th</sup> April a referral was made to PC for care of ZZ's partner (P2). The same carer was to provide care for both P2 and ZZ. This continued (except for a further period of hospitalisation in 2013) until P2 died in May 2013.

5.18. On 25<sup>th</sup> April the record of supervision of SW1 states: "there has been an agreement regarding housing and work will be starting in due course. In the meantime ZZ has a care package of 3x daily due to her husband who is her carer being admitted to hospital". [*This does not appear to have caught up with the fact that both P2 and ZZ were now receiving care as P2 was now home from hospital*].

5.19. A *Dignity Promise* was signed on 16<sup>th</sup> May by carer 1 as follows:

"My Dignity Promise

- I will call you by the name you prefer.
- I will do all I can to keep you safe.
- I will treat you with dignity, respect, courtesy and consideration.
- I will promote your independence, well-being and choice.
- I will respect your individuality.
- I will respect your right to privacy.
- I will help you to have greater control in your life.
- I will act on any comments, concerns or complaints you may have.
- I will always remember that I am a guest in your home.
- I will engage with family members and carers as care partners."

5.20. PC introduced this 'Dignity Promise' and all staff were required to commit to it. It was intended to demonstrate PC's commitment to delivering service with respect and dignity and set high standards for all staff to follow. This was also signed by carer 2 on 17<sup>th</sup> May 2012.

5.21. On 16<sup>th</sup> May a social work assessment was recorded by another social worker (SW2) stating that ZZ's needs were classified as "substantial". The following detail was included on the record: "Risk of malnutrition, falls and self-neglect". "ZZ is unable to negotiate stairs and therefore she cannot access bathroom on the upper floor of her flat. She is unable to stand for more than a couple of minutes." "ZZ has been housebound for years as she doesn't like open spaces." "Council tenant."

5.22. On 25<sup>th</sup> May a support plan in respect of ZZ was recorded by SW1. It stated that the home care package of 15.25 hrs per week (three visits per day) was to: "provide support and assistance with personal care and domestic tasks while carer is in hospital"; "ensure ZZ's personal hygiene is maintained"; "ensure adequate nutrition intake as ZZ is unable to prepare any meal." "Morning visit to include strip wash." There is a comment from PC on the chronology submitted for this review stating: "There is no evidence in PC's file of the Council conducting a review visit to ZZ in 2012". There is also no evidence that PC chased the Council to highlight that a review visit would be desirable. [*The lack of communication across PC and ASC on the issue of reviews is a significant issue*]

5.23. In June ZZ officially notified the Housing Department that P2 had moved in to care for her.

- 5.24. On 20<sup>th</sup> June a record of supervision of SW1 records: "Client has mobility issues, reduced balance, breathing issues, agoraphobia, depression. Care working well to meet her needs...Plan to transfer case for reviews."
- 5.25. On 14<sup>th</sup> August a home visit by SW1 recorded: ZZ "lay at the sofa and according to P2 this is how she spends her day." The record says that SW1 informed them that "since their care needs are stable I will be closing the case".
- 5.26. A subsequent transfer summary of the case of ZZ on 21<sup>st</sup> September states: "No outstanding issues identified or reported. Case to be transferred for yearly review". The case was closed to any active social work involvement with a note on the system that ZZ's circumstances were to be reviewed in 2013.
- 5.27. In October ZZ refused a flu vaccination offered by community nursing. The GP recognised the need to review: "patient needs review, blood tests and blood pressure check". ZZ however turned this review down on receiving a telephone call from the GP, saying she would make contact if unwell.
- 5.28. There were two contacts in October and December regarding arrears/ repairs with the Housing Department.

### **2013**

- 5.29. On 2<sup>nd</sup> January and again in December 2013 PC telephone surveys were carried out with ZZ. Her response to this is recorded as: "All my carers treat me kindly." ... "I am happy to have [carer 1] as my carer." (PC conducts telephone surveys of service users to gauge their satisfaction and views about the service). This survey was conducted by a Service Team Leader for the area where ZZ lived.
- 5.30. In January an annual quality monitoring review of ZZ's service was conducted by PC. It was concluded that there was no change required to her service and ZZ was pleased with the service she was receiving. Feedback on carer 1 from ZZ is recorded as: carer 1 "is an excellent worker and a wonderful person." On site supervision of carer 1 with another service user elicited similar feedback: "She is my angel. I cannot do without her. Has good personality and a good worker." An annual appraisal of carer 1 was carried out on the same day.
- 5.31. The Service User Plan at this time noted:
- 'Care Worker to support and encourage ZZ to do as much as she can and help when needed.'
  - 'Care Worker to support and encourage ZZ's independence.'
- 5.32. A new manual handling assessment was conducted. It noted:
- 'House bound.'
  - 'ZZ can't weight bear and limited upper body strength.'
  - 'Sleeps on the sofa, can manage.'
  - 'Care Worker to assist with strip wash.'
- 5.33. Similarly at the end of April and again in October, supervision of carer 1 by PC elicited more positive feedback about carer 1's performance from service users. As had been the case in 2012, PC records that during neither of these supervision sessions was there any recorded indication from carer 1 of concerns about ZZ. Supervision of carer 1 in October also referred to "Most of [carer 1] Service Users

are very challenging, due to dementia but [Carer 1] works with them exceptionally well”.

- 5.34. 26<sup>th</sup>/ 27<sup>th</sup> February and 7<sup>th</sup> March a Care Quality Commission (CQC) routine/ scheduled inspection of PC was carried out. All outcomes were found to be compliant.
- 5.35. In April P2 was admitted to hospital again. ASC records dated 24<sup>th</sup> July give the date of death of P2 as 21<sup>st</sup> May. *[This has been checked with the registrar due to discrepancies in the date of death of P2. The officially recorded date of death is 22<sup>nd</sup> May 2013].*
- 5.36. On 27<sup>th</sup> June carer 1 was awarded the NVQ Level 3 Diploma in Health and Social Care.
- 5.37. On 24<sup>th</sup> July SW2 carried out a review with carer 1 present during a lunchtime call. ZZ had requested the review take place with the carer present as she was “unable to open the door”. The review recorded: “No change to current care package with PC as identified needs are being met successfully”. The record shows that carer 1 advised that “ZZ does not leave the living room and spends most of her time sleeping on the settee”; “refused to have her radiators changed (Home Improvement Scheme)”; and “ZZ stated that her current identified needs are being successfully met with her current care package and that she does not require additional support and assistance.” This review recorded that ZZ was not a risk to herself or others (despite risks having been identified in May 2012) with no record of any exploration of these. The view of carer 1, that the care package worked well and there were no issues with it, was recorded on the assessment.
- 5.38. The carer did however express concern that ZZ spent all her time on the settee and had declined bereavement counselling. In this context the assessment recorded that ZZ had capacity to make informed choices. *[Despite the carer indicating at this ASC review in July an awareness that P2 had died, the chronology submitted to the SCR by PC includes oral evidence given by the manager/ supervisor of the carer that ZZ had advised that P2’s death was on 12<sup>th</sup> August].* As in 2012 (see paragraph 5.22) there is a comment from PC on the chronology submitted for this review stating: “A review of ZZ’s service should have been conducted by the Council in July 2013; however if it was PC was not sent any new paperwork or outcome of the review. There is no reference in the log book to a review taking place. Council reviews are supposed to happen annually but it is not uncommon for them not to take place”.
- 5.39. In August the log entries in ZZ’s daily log book completed by carers (given below) give an impression of the tasks carers recorded as being carried out for ZZ at this time:
- 5<sup>th</sup> August: “Served her...breakfast 2 ham sandwiches and washed her face and strip wash and changed her clothes. New clothes for her and changed her pillow cases and opened windows and curtains and empty and cleaned commode and washed up and tidy up and fresh water for her. ZZ’s birthday today.” Recorded by carer 1

8<sup>th</sup> August: "On arrival [ZZ] lying in settee. Prepared ham sandwich, bottle water, washed up. S/U [ service user] had washed and dressed, hair brushed. Self-medicated. Prepared 6 cigarettes on table as requested by S/U as instructed. Draw curtains and opened side windows, remove covering over bird cage. Left S/U lying in settee." Carer 3

9<sup>th</sup> August: "Opened curtain and window, removed bird's covering off cage. Prepared ham sandwich and cup of tea. Self-medicated, washed and changed clothes, emptied used cigarettes and garbage, emptied and washed commode. Left a bowl of water with bleach as requested by S/U. Provided water. Left OK". Carer 3

5.40. P2 was recorded in the PC IMR as having died on 12<sup>th</sup> August 2013. *[Because of a discrepancy in the recorded date of death by PC and by ASC this date was checked with the registrar. The officially recorded date of death of P2 is 22<sup>nd</sup> May 2013].*

5.41. On 17<sup>th</sup> August the carer recorded: "She didn't want anything to eat. I sit and had a long chat with her."

5.42. In October ZZ again refused a flu vaccination.

5.43. On 11<sup>th</sup>/ 12<sup>th</sup> December and 10<sup>th</sup> January 2014 a CQC routine/ scheduled inspection of PC (King's Cross Office) took place. The relevant CQC report was published in February 2014. There were no issues raised about any aspect of the PC service. The report's conclusions were:

- Respecting and involving people who use services – Met this standard
- Care and welfare of people who use services – Met this standard
- Safeguarding people who use services from abuse – Met this standard
- Supporting workers – Met this standard
- Assessing and monitoring the quality of service provision – Met this standard.

Feedback comments from service users included: "I am very happy with my regular care worker who has helped me over the last 5 years" and "The carers look after me very well, I don't know what I'd do without them."

5.44. On 20<sup>th</sup> December PC met with the Council to discuss arrangements regarding a new home care contract. The Council said that they expected to review each of the service users at their normal annual review and at the point of review the service users would either transfer to a new provider or be given the option to stay with PC using a Direct Payment. However, the Direct Payment rate was £12 per hour which PC did not believe was sufficient to provide a safe service in the long term. It was anticipated that unless service users chose to stay with PC on a Direct Payment (which was not a viable option in the long term), by November 2014 all Service Users would have been reviewed and transferred to new providers.

## **2014**

5.45. In January a review of ZZ's service was conducted by PC. There was no change indicated as being needed to the service and again ZZ is recorded as saying that she was very pleased with the service being provided by carer 1.

5.46. A new manual handling assessment was conducted. It noted:



- “House bound.”
- “ZZ can’t weight bear and has limited upper body strength.”
- “ZZ is house bound and does not like going out.”
- “ZZ sleeps on the sofa in the living room.”
- “Able to transfer onto commode.”
- “Care Worker to assist with strip wash.”

5.47. Supervision of carer 1 at this time again records positive feedback from service users and again PC point out that nothing in the supervision notes indicates that carer 1 mentioned any problems with ZZ. An annual appraisal of carer 1 was again carried out. Again telephone surveys were carried out by PC in February and March as in previous years. ZZ is recorded as being totally satisfied with the service. In June supervision of carer 2 is recorded and in respect of service user feedback it is recorded that ZZ had no concerns.

5.48. It is recorded by PC that in January ZZ was offered a bed by ASC but turned this down.

5.49. On 3<sup>rd</sup> February the Assistant Director of ASC and Joint Commissioning wrote to service users to advise of changes to the home care service. ZZ was distressed by this letter and said to her carer that if they took carer 1 away from her she would kill herself. Carer 1 reported this to the office and the duty worker at Camden Council was informed on 19<sup>th</sup> February. The duty worker said that he would speak to ZZ and contact PC if there were any concerns. He said that the Council should be contacted if there were any further concerns about ZZ. PC spoke to ZZ and reassured her that carer 1 was not being taken away from her and this seemed to ease her anxiety. There is a comment from PC on the chronology: “In hindsight, this telephone call should have triggered a review visit by Camden Social Services to ZZ. (If a review visit was undertaken by the Council it did not result in any paperwork being sent to PC).”

5.50. In February and March the following are examples of entries in the PC daily log (entered by the carers):

24<sup>th</sup> February: “Wash and dress, put cream on. Gave her B/F [*breakfast*]. Empty commode, wash dishes. Tidy up. She is fine” (Carer 2). This was entered by the carer for many of the lunch time calls.

1<sup>st</sup> March: “ZZ not feeling well and refused to call doctor. And she doesn’t eat nothing or drink, empty and cleaned commode” (Carer 1). By evening she was better and ate ham sandwich and drank fresh water according to the log book.

6<sup>th</sup> March: “strip wash and cream” in care log and “she is fine”.

15<sup>th</sup> March: the log entry includes: “Wash her face and body. Washed and empty the commode” (Carer 4).

19<sup>th</sup> March: the log entry again says: “she is fine.” “Strip wash and dress, put cream on” (Carer 2).

5.51. On 8<sup>th</sup> April there is a letter from N1 to the GP practice regarding medical support for Attendance Allowance. This stated that ZZ didn’t want to see a doctor. It

explained her anxiety in respect of doctors. It indicated in a copy of a letter to the Department for Work and Pensions that N1 may have to withdraw much of his support if this financial assistance was not forthcoming.

- 5.52. The safeguarding meeting following ZZ's death ascertained that the last prescription for ZZ was issued in April 2014 (no evidence of physical examination or evaluation).
- 5.53. PC recorded that they had been chasing the Council since December 2013 for a spread-sheet of service users and the dates of their scheduled reviews. This spread-sheet was finally received on 14<sup>th</sup> April 2014. It included ZZ who was scheduled for a review in July 2014 although there had been no information received by PC of a review in either July 2012 or July 2013 *[even though the carer was present at the July 2013 review]*. A number of service users had no review dates listed against their name. When asked about this, the Council responded: "You will notice some customers do not have a date yet. Annual reviews are resource intensive for ASC and they are currently looking at how this can be addressed...ASC have put in place quality and pricing criteria to help prioritise organisations and reviews of customers, based on these criteria I have been advised that PC is low priority." PC contacted the Council to ascertain what had been the outcome of the reviews which had been conducted but did not receive a response.
- 5.54. A police interview with the team leader at PC elicited that carer 1 was on holiday at some point during May. When she returned a new carer shadowed her for several days as part of induction training.
- 5.55. Further log book entries by carers give some impression of care activity:
- 22<sup>nd</sup> April: "P/C [*personal care*] and put cream and dress on. Gave her B/F. Empty commode, wash dishes, tidy up. She is fine" (Carer 2).
- 19<sup>th</sup> May: "Made her sandwich with ham and butter. Gave her P/C. Empty commode and bin. Tidy up, wash dishes. She is fine" (Carer 2).
- 23<sup>rd</sup> May: "P/C and dress. Gave her B/F, slice of bread and ham, butter. Empty commode, wash dishes, tidy up. She is fine" (Carer 2).
- 28<sup>th</sup> May: "Gave her wash and dress, put cream on. Gave her B/F, slice of sandwich with ham, butter. Empty commode, wash dishes, tidy up. She is fine." (Carer 2).
- 29<sup>th</sup> May: "Made ZZ ham sandwich and drink. Washed up, tidy kitchen, assisted wash hands and face. Left her comfortable" [*No reference to personal care on this evening call*]. (Carer 5).
- 3<sup>rd</sup> June: "Made her dinner, ham sandwich and fresh water and washed her face and her hands and washed up and tidy up. Her nephew with her" (Carer 1). [*No reference to personal care*].

4<sup>th</sup> and 5<sup>th</sup> June: there are similar entries with no reference to personal care for example on 4<sup>th</sup> June: “Made her sandwich with ham, butter. Wash dishes, tidy up. Empty commode. She is fine” (Carer 2).

5.56. 2<sup>nd</sup> – 6<sup>th</sup> June: A new carer was shadowing carer 1 as part of her induction. During a police interview this carer said that she had suspected that ZZ was hiding something such as pressure ulcers under the blanket [*when she saw that ZZ was lying on the sofa with a blanket pulled up over her*] and had said this to carer 1 who had responded that ZZ was not showing any signs of pain. The carers decided to report the situation to the PC office.

5.57. 5<sup>th</sup> June: Carer 1 went into the PC office with the new carer. Carer 1 stated that ZZ was refusing to have a wash. Carer 1 said that she would usually assist ZZ by washing her face and hands and ZZ would state she would wash below, but now she was refusing all personal care saying she would do it later. Carer 1 said she had tried leaving a bowl of water with a wash cloth folded in such a way to indicate if ZZ had had a wash, but when she returns it is in the same position. Carer 1 also stated that ZZ was lying on her settee covered with her duvet right up to her neck clutching it tightly. The team leader asked carer 1 when ZZ had started refusing personal care from her but she was unable to give a date.

5.58. The team leader advised carer 1 on her next visit to have a conversation with ZZ privately and ask if she required a GP or an ambulance and, if ZZ refused, to state that PC had a duty of care. The team leader informed carer 1 that she was concerned if ZZ is lying on a settee as a bed, refusing care, what was she hiding under her duvet? The team leader also asked carer 1 to write a full detailed report about her concerns from the time ZZ refused to allow her to assist with her personal care so that the team leader could inform ASC. [*This response from the team leader lacks urgency given the nature of the concerns*].

5.59. Further care log entries:

6<sup>th</sup> June: “Made her 1 slice of sandwich with ham, butter and water. Empty commode, wash dishes, tidy up. She is fine. She has no bowel open” (Carer 2). [*Again no personal care is recorded*].

On the same evening carer 1 recorded that ZZ was still refusing personal care and still no bowel open.

7<sup>th</sup> June (morning): “Made her B/F ham sandwich and fresh water. Still refusing P/C, she said “don’t ask me about it, you upset me” and washed her face and her hand. Empty, cleaned commode and washed up and tidy up. Left OK. Changed her water bowl and cloth as usual. No bowel open” (Carer 1).

7<sup>th</sup> June (lunchtime): “Served her ¼ ham sandwich and fresh water and cleaned window sills and left OK. Her movements been very slow recently, even when she sign time sheets” (Carer 1).

7<sup>th</sup> June (evening): “Made her ham sandwich today she had only ¼ of ham sandwich and she said not hungry and fresh water. Nephew came today” (Carer 1).

8<sup>th</sup> June (morning): “Still refusing P/C. Made her ham sandwich she had only ¼ of sandwich keep other in the fridge. Fresh water and empty and cleaned commode and washed her face and her hands, and empty bin. Washed up and tidy up. She has no bowel open” (Carer 1).

8<sup>th</sup> June (lunchtime): the log recorded that ZZ still had not opened her bowels and that ¼ of a ham sandwich was served for her. *[It is not clear if this was eaten at this point or others]* (Carer 1).

8<sup>th</sup> June (evening): “ZZ doesn’t want to eat her dinner. She said she is not hungry. I called the office about it. She just had her water. No urine in the commode. No bowel open” (Carer 1).

5.60. Carer 1 called the PC out-of-hours service during her evening call concerned that ZZ wasn’t eating. She said that she had advised the office (on 5<sup>th</sup> June). She asked the out-of-hours coordinator to call the service user and ask her (ZZ) to try to eat something. Carer 1 said she thought the office needed to contact ASC or she would have to write to them because she (ZZ) was getting worse. She was going to talk to the team leader on the Monday. She said that ZZ was drinking water but not eating. The out-of-hours coordinator said she would speak to ZZ and ask if she needed anything. She did this by telephone saying that she wanted to make sure that the carer was looking after ZZ properly and feeding her. ZZ answered that the carer was looking after her very well but she didn’t want to eat because it was too hot. She said she had a glass of water which she was drinking and she was ok. ZZ was asked if she would eat a little something and she said no. She then suggested the carer would leave her a sandwich for later and she said she couldn’t eat because of the heat. She said she was ok and would eat breakfast in the morning. The coordinator then spoke to carer 1 and asked her to leave a sandwich in case ZZ wanted it later. Carer 1 said she would make a sandwich and that ZZ was taking small sips of water. The coordinator rang the operations manager to advise her. This manager told her to write it in the hand-over book and speak to the team leader about it on Monday morning.

5.61. On 9<sup>th</sup> June carer 1 submitted a written report before attending the morning call to ZZ.

5.62. The log book entry for 9<sup>th</sup> June at 10am said: “ZZ not well at all. Call 999. She doesn’t want to go to the hospital. Call another doctor. I am still waiting. Call the office. When I approached her bed sores and very bad condition, refused to change her top and bad smells. Waiting for nephew” (Carer 1).

5.63. At 10:15am carer 1 called the PC office and spoke to the care coordinator and said that she was very concerned about ZZ’s wellbeing. The coordinator asked her if she had called the GP and she stated that she offered but ZZ refused. The coordinator then rang ZZ’s landline. When she answered the phone the coordinator could hear the weakness in her voice, it was not her usual voice. She asked if ZZ was okay and ZZ kept saying “I need some water, I need some milk”. The coordinator asked if she would like the GP; she said no.

5.64. The coordinator immediately rang carer 1’s mobile phone and asked her to ring the GP and explain her concerns. Carer 1 called back and said the GP practice had

asked her to call back later. The coordinator then instructed her to call an ambulance because PC had a duty of care, and she should keep her updated. The carer called back and informed the coordinator that the paramedics were there, but ZZ was refusing to go to the hospital and the paramedics said they cannot force service users to go, but they will contact a doctor to visit her at home.

- 5.65. The coordinator contacted ASC and informed them of the situation. ASC asked to be informed of the outcome and agreed to pay the carer for the extra time.
- 5.66. Carer 1 went to the PC office at about 2.00pm to say the doctor had visited and ZZ had been taken to University College London Hospital, and she was in a bad way, that there were pressure ulcers and they smelt.
- 5.67. The team leader telephoned ASC to inform them that ZZ had been taken to University College London Hospital and informed the duty worker that ZZ had pressure ulcers on her body. Carer 1 had said that she only noticed them when they removed ZZ from the sofa.
- 5.68. On admission to University College London Hospital ZZ's condition was described as follows: "Unresponsive; BP [*blood pressure*] unreportable; covered in dried faeces; contracted limbs; poorly kempt; septic shock, probably from pressure ulcers." She was described as malnourished. Her weight was estimated at 30kg (4stones 10lbs) and her height 1.50metres (4 feet 11inches) She was at very high risk of re-feeding syndrome. She was covered in 13 pressure ulcers, nine of which were graded four.
- 5.69. ZZ was described by a member of nursing staff as follows:
- "ZZ was emaciated. She was covered in her own faeces which was stuck to her skin. I would describe it like snake skin it was stuck all over the lower part of her body, legs and feet it must have been there for months. Her body was badly contracted she looked like she had been in that same position for a very long time, she would not have walked for a long time as her legs were locked. We tried to move her arms and legs to expose the sores but her joints were locked as her elbow was moved it went straight into her abdomen as it was locked"
- 5.70. The University College London Hospital IMR states that "A critical care consultant said "the lack of muscle and deterioration of her body was one of the worst cases he had seen in his career"."
- 5.71. The subsequent safeguarding meeting notes state that "medical feedback on the extent of ZZ's body sores and the putrid smell...would have made it impossible not to know something was badly wrong."
- 5.72. Safeguarding referrals were made by the ambulance service, the GP and University College London Hospital (the latter at 2pm on the day of admission).
- 5.73. ZZ died on 10<sup>th</sup> June at 5pm.
- 5.74. On 10<sup>th</sup> June ASC procurement requested an inquiry into the practice of the carers and set in motion contact with other service users.

- 5.75. On 11<sup>th</sup> June and 9<sup>th</sup> July safeguarding adults strategy meetings were held and clear actions were put in place to safeguard others and to ensure an effective investigation.
- 5.76. In June 2014, CQC carried out a responsive inspection of PC in light of the concerns surrounding ZZ. Major failings were found on inspection against outcomes for care and welfare, safeguarding, staffing, staff support and assessing and monitoring the quality of service provision. All were found to be in breach of regulations.
- 5.77. On 31<sup>st</sup> July ASC confirmed that 44 people considered most at risk had moved to a new provider. The 90 remaining people using PC King's Cross service were expected to move to a new provider by 22<sup>nd</sup> August 2014.

## 6. ANALYSIS AND LESSONS LEARNED

6.1. The purpose of this analysis is to identify the most pertinent lessons to be learned from the circumstances surrounding the death of ZZ and to offer recommendations for acting upon these across the whole SAPB in Camden. The emphasis in this review is on recommendations for a necessary shift in practice for the *whole partnership* rather than to focus on the shortcomings of any particular individual or agency. That is not the purpose of this review. The overriding objective is to try to prevent similar outcomes to those suffered by ZZ arising in the future. This analysis draws on relevant research which must inform improvements.

### 6.2. Identified good practice

- 6.2.1. There was a range of good practice identified across agencies. The following stand out as examples of this which can helpfully inform practice:
- The swift response of LAS, the GP and University College London Hospital in recognising that a safeguarding alert was required to be raised.
  - The robust gathering of evidence by the University College London Hospital.
  - Housing Department responses (in respect of arrears and ZZ's reticence to allow necessary work to be carried out) which referred to background information about ZZ (who she was, what was difficult for her and why) in coming to compassionate decisions.
  - The coordination and recording of multiagency safeguarding meetings with clear action planning and accountability for actions and following up whether these had been carried out.
  - Escalation of concerns within University College London Hospital.
  - Escalation of information within ASC following receipt of the safeguarding alert.
  - Learning needs/ opportunities highlighted for PC in ASC procurement monitoring meetings were followed up, for example in the context of repeated issues in respect of financial abuse. This issue was the focus of a provider forum to support learning and development.
  - Regular liaison between the Council commissioning and procurement team and CQC and PC.

- The practice in University College London Hospital that offered counselling and debriefing to staff who had cared for ZZ.
- The commitment across all agencies to learning necessary lessons from the circumstances surrounding the death of ZZ and to putting in place and carrying out comprehensive action plans to respond to those lessons in practice.

6.2.2. ZZ neglected to attend to her basic needs or at times to accept support with those needs (nutrition; hydration; personal hygiene; health needs amongst these). She was at risk on a number of levels which will be explored. She was reluctant to engage with services and support offered. The two themes of self-neglect and working with risk are therefore centre stage in analysing practice and the steps that might be taken to mitigate against similar circumstances arising in the future. These two central themes will be explored with reference to a number of significant and related aspects of policy and practice. A focus on the person and the professionals'/ workers' relationship with them emerges as critical both in the case of ZZ and in relevant research, case law and other practice experience (for example in other SCRs) in situations where self-neglect is a feature. Practice needed to begin with such a focus. This is the starting point of this review.

### 6.3. A focus on the person

6.3.1. A focus on ZZ, her background, her preferences, what and who she valued and found helpful, her anxieties, her needs...in short, who she was, was missing in case records. Busy and sometimes overloaded professionals and staff overlooked this focus in favour of following processes and ticking boxes.

#### ***Regulation and procurement: towards person-centred outcomes***

6.3.2. The pursuit of compliant following of processes and ticking of boxes in the case of ZZ sometimes masked the reality and meant that key professionals (regulators, commissioners, supervising managers) stopped short of noticing that this focus on 'the person' was absent. The regulator and ASC People Services Procurement are committed to a more person-centred methodology. This is crucial if there is to be robust scrutiny as to whether the rhetoric of personalised services is turned into reality by commissioners and providers.

6.3.3. It was clear for example that PC and its staff knew the rhetoric and an example of this is set out in paragraph 5.19 (above) in the form of the *Dignity Promise* that was signed by care staff including carers 1 and 2. It is imperative that this isn't just about reading and signing the promise but about really understanding the implications, integrating this into training and helping carers to recognise the dilemmas in balancing the component parts of this (service user choice and control with wellbeing and keeping the service user safe). Training, guidance and support needs to be clear and demonstrate that if the carer is struggling with that dilemma it must and can be escalated for effective support from a senior member of staff. Regulation and commissioning (as well as staff supervision) needs to test out the ability of carers to apply these principles in practice to real practice dilemmas and test out the support and guidance of managers.

- 6.3.4. ASC procurement has re-commissioned home care services to “create a framework for person-centred home care.” A key aspect of this was “a move to commission care by personalised outcomes as opposed to a time and task model.” There was some evidence of this in the tendering process within the new home care framework. For example in the quality assessment of providers PC did not meet the required threshold because of issues including: a focus on information collection rather than how this is used to improve quality; and in the required presentation of a case study there was insufficient content on how specifics of customer needs would be addressed. These are attempts to get to the bottom of what a service is really doing to make person-centred outcomes a reality and how in practice the dilemmas of meeting outcomes and the negotiation with service users around choice, wellbeing and safety really works, rather than what is said ‘on paper’. This emphasis in procurement needs to be developed even further.
- 6.3.5. This inability of PC to meet the required thresholds in the tendering submission may perhaps be indicative of an organisation with an emphasis on systems rather than on outcomes and people. This may be the case since some of these issues in this tendering process were reflected elsewhere in the practice of PC, see for example in paragraphs 6.3.3; 6.4.21; 6.4.22. (It should be noted that PC did submit a price that was above the ceiling rate for Camden but from the perspective of procurement services were eliminated on quality issues including the above areas in paragraph 6.3.4 above).
- 6.3.6. The new approach within procurement reflects national guidance. For example guidance on commissioning for better outcomes published in 2014<sup>2</sup> gives advice on achieving person-centred commissioning which is focussed on outcomes: commissioners should “work closely with providers to promote flexible, innovative person-centred models of care, which reflect the outcomes people want and balance choice and control with risk....” And should “ensure that personal outcomes are being achieved through effective care management processes, good quality relationships with care and support staff and a focus on wellbeing.” ASC procurement must consider how it can support the embedding of these principles as it further develops and embeds the emphasis on the person and outcomes.
- 6.3.7. From the regulator there is a commitment to a greater focus within inspections on making it easier for people, their families and staff to tell CQC about their experience of care and *using* this to drive improvement in practice. The views of a greater number of people receiving services will be heard. Experts by experience are also part of the inspection team. There is an emphasis on bringing specialist knowledge and expertise into the inspection regime, there is an emphasis on identifying patterns of concerns and triggers to pick up on early warning signs. There is an associated increase in capacity of the regulator to make the system more robust and more detailed tools to support inspections. All of this is new and still needs to be tested out and its impact analysed.

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<sup>2</sup> University of Birmingham, Health Services Management Centre and Institute of Local Government Studies, (2014). [“Commissioning for better outcomes: a route map”](#). (Supported by Department of Health (DH); Association of Directors of Adult Social Services (ADASS); Local Government Association (LGA); and Think Local Act Personal (TLAP)).



- 6.3.8. What is crucial here is that these person-centred principles driving practice in regulation and procurement impact upon the practice of front line carers and outcomes for people.

***Front line practice and the issue of a focus on the person***

- 6.3.9. Whilst we know something of the characteristics of ZZ from interviews with significant others as part of this review, the records of those who engaged with her support needs betray a lack of enquiry and insight into ZZ ‘the person’. This lack of insight meant there was nothing that would give a professional or carer a “way in” to make a connection with ZZ as a way of supporting discussion of the problematic issues that were to lead to her death. There was instead an unquestioning acceptance of the wishes she expressed, that she had capacity and that therefore all those involved must go along with her wishes.
- 6.3.10. ZZ neglected her own health and care needs and was reluctant to allow others to offer support. The most recent research on self-neglect<sup>3</sup> is therefore of help in looking at lessons from the situation involving ZZ. It sums up how good practice looks: “Effective engagement and intervention was ... based on a willingness to express concerned curiosity. Rather than say, “it is not for me to judge”, which would result in overlooking a duty of care to that person, managers recognised that it was important to ask questions around why an individual lives in a particular way, and what might have happened in that person’s life to have led to the circumstances they now find themselves in. This recognises the influence of a person’s history and the challenge of “dealing with the consequences of that today”.”
- 6.3.11. This research<sup>3</sup> is grounded in the experiences of people with first-hand experience of situations involving self-neglect. It seeks approaches that produce positive outcomes from the perspectives of those involved. It offers some important lessons for practice. A series of in-depth interviews was undertaken with 20 managers, 42 practitioners and 29 people who use services across 10 authorities. A prominent finding of this research is the importance of “finding the person”: the practitioner exploring and understanding “the individual’s life history, and its possible connections with current patterns of self-neglect. Early experience, trauma, loss and relationship all figured strongly in the service users’ stories.” Practitioners worked with “the fear, anxiety, embarrassment and shame that were sometimes present....” This approach was absent in professional dealings with ZZ. It is clear that it was necessary.
- 6.3.12. It is perhaps significant that ZZ’s nephew (N1) recalled (when taking part in this review) how when ZZ’s partner, P2, went into hospital in 2011 his aunt rang N1’s father and asked him to move in with her because she didn’t like being on her own. Then she asked N1 the same question. Each time she had lost a partner in the past they were soon “replaced” by another. These issues of fear, anxiety of being alone, of depression and bereavement were not explored with ZZ and might have been considered as potential reasons for her self-neglect if professionals had engaged with her and with her family. Anxiety was a consistent theme for ZZ.

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<sup>3</sup> Braye, S.; Orr, D.; Preston-Shoot, M., (2014). “[Self-neglect policy and practice: building an evidence base for adult social care](#)”. SCIE report 69, London (commissioned by DH).

- 6.3.13. Those who worked with ZZ mostly did not engage with her in this way. An exception was the Housing Department whose IMR reflects a greater level of understanding of her biography and of the issues that were relevant: reluctance as far back as 1982 to claim benefits as she “didn’t want charity from the social”; that she was anxious and socially isolated and that there was a formal diagnosis on record by the GP of agoraphobia. Housing have on record a record from a GP medical report when a referral was made in 1984 to a consultant psychiatrist “because her neurotic symptoms had become so pronounced” and that she was “a vulnerable, anxiety prone woman who has become lonely and probably depressed...by the sudden loss of companionship.” The record states that “follow up appointments with the psychiatrist had not been kept.” In 1992 a housing officer was concerned that ZZ might be paying too much of her arrears and visited to discuss paying less. She noted the flat badly needed redecorating. ZZ’s arrears were written off and the flat was re-decorated. On 23<sup>rd</sup> February 2012 the housing manager expressed concern about the effect on ZZ of legal action in respect of her refusal of entry to do essential repairs to heating system. Housing clearly considered these particular issues in April 2012 against a backdrop of the information they had about ZZ’s anxiety, agoraphobia and a partner in hospital and about to be discharged with breathing difficulties.
- 6.3.14. ASC, in the first assessment in December 2011, sought out no background information, no information about ZZ’s strengths, preferences or aspirations nor anything about her support network. Throughout ASC’s involvement there is a lack of proactive engagement with ZZ or with her nephew, with little acknowledgment of the significant role he played apart from reference to him in the July 2013 assessment. There is no mention of other family members or of family history even though family members kept in touch with ZZ by telephone each week and visited occasionally. The ASC IMR acknowledges that ASC did not know what the nephew did for ZZ in respect of helping with money and shopping. It acknowledges a significant lesson to be learned “to ensure that ASC assessments are more personalised, outcome/ reablement focused, and proactive in identifying and preventing risk.”
- 6.3.15. There are inaccuracies in records that underline the lack of a connection with ZZ’s life and relationships. In May 2012 the ASC assessment states that ZZ “does not have any support network apart from her neighbours (NB2) who assisted with shopping and finances when her partner was in hospital”. This is not the case. Her neighbour passed this responsibility on to her nephew when her partner (P2) was in hospital in 2011. P2 is referred to as her husband in the first support plan of December 2011. The PC service user plan replicates this error on 9<sup>th</sup> December 2011 referring to the next of kin as ZZ’s husband.
- 6.3.16. In the July 2013 review undertaken by ASC carer 1 from PC, who was present, referred to ZZ declining bereavement counselling and that she spends all of her time on the settee and does not wish to go out. There is no evidence that this is explored. It is concluded that ZZ has capacity and was physically well and able to make an informed decision on these issues. Neither the interrelationship of these issues nor their broader impact was acknowledged or considered. It is noted by a number of agencies in this SCR that insufficient weight was given to the significance of the death of P2 for ZZ. *[Indeed there is confusion in reports for this SCR, as above, in understanding when P2 died].*

- 6.3.17. PC's records also convey an absence of any sense that carers developed any understanding of, or engaged to any great extent with, ZZ "the person". There are isolated glimpses in records of the person: ZZ's birthday today referred to (5<sup>th</sup> August 2013); and the fact that carers refer to covering over a bird cage. Despite frequent reference to "she is fine", there is no reflection in records of engagement in conversation with her about reluctance to eat or to have personal care tasks performed or about more general matters that might have offered a way in to discussion of those issues.
- 6.3.18. A lack of connection or discussion with ZZ was partly responsible for a lack of insight into a number of issues that were key to ZZ's health, safety and wellbeing. These are set out below. They include ZZ's alcohol consumption, her reluctance to eat sufficient or nutritious food and reluctance to accept medical intervention/ support.
- 6.3.19. In May 2012 an assessment by SW2 refers to high risk of falls due to poor mobility and *alcohol abuse*. There is no qualification of this statement. We are aware that the nephew purchased wine on her behalf but not whether this was an excessive amount or whether ZZ's drinking habit constituted "alcohol abuse". There is no analysis or any attempt to discuss the issue and any associated implications or potential risks.
- 6.3.20. The support plan requested of PC by ASC in December 2011 when ZZ's partner was admitted to hospital (subsequently drawn up in a formal support plan by PC on 9<sup>th</sup> December 2011) states: "If ZZ refuses to have breakfast carers to prepare a snack and leave it on the table so she can have it later on." This statement is cut and pasted to the evening visit as well. There is no explanation or exploration of why this is stated and whether refusal of food is a recurrent or significant issue in respect of ZZ. We are aware that at some point ZZ began to exist on a diet of sandwiches every day and all day. In answer to a question posed by the SCR panel ASC advise: "records indicate that ZZ was unable to prepare meals, and according to the next door neighbours who provided some care and support, she had only eaten a sandwich a day for three days at the time of the December 2011 assessment after her husband was admitted to hospital". It is likely that this was the point at which the pattern began to be established and there was later further deterioration. ASC go on to state: "One can surmise that the bereavement may have contributed to her lack of inclination to eat. Certainly there was a decline and at the very end of her life it appeared that she had difficulty in eating even a quarter of a sandwich".
- 6.3.21. The ASC IMR acknowledges ambiguity on this point and states: "If it were true that ZZ refused meals altogether, and this was known to the social worker, this is not clearly indicated in the records, and would reflect the poor quality of the assessment. There is insufficient evidence to come to a conclusion about this".
- 6.3.22. ZZ was reluctant to accept any medical intervention. Conversations with family members shed some light on the longstanding nature of this response. Their insights are set out in paragraph 4.7.4 (above). Professionals had no such insight. There were signs of medication not being taken but this was not an issue that carers, social workers or the GP picked up on. ZZ was recorded in assessments as administering her own medication and there was not a focus on

the issue. According to her nephew (when speaking as part of this review) ZZ said she didn't take her tablets because she felt better without them. It is not noted in records that professionals were aware of this. The GP practice was unaware she was not taking her medication and indeed the fact that ZZ failed to collect her prescriptions meant that medication reviews were not triggered. Even before this ZZ declined to engage with such reviews but this was not proactively followed up.

- 6.3.23. Opportunities were missed to achieve any real level of understanding alongside ZZ of presenting issues such as the above. There is no evidence of any efforts to explore the nature, extent or reasons behind these with her.
- 6.3.24. Neither was there engagement with ZZ's family. There was a missed opportunity in April 2014 when ZZ's nephew (N1) indicated clearly in a copy to the GP of his letter to the Department for Work and Pensions (re. Attendance Allowance) that the support of ZZ was placing a significant burden on him. There was no conversation with N1 about possible communication of this to other professionals to facilitate appropriate support/ assistance. The letter clearly indicates that "the last 8 years she has been confined to her sofa...this is where she spends her day and sleeps, she can take only a few steps to the commode then back to the sofa...she stays on the sofa in the front room day and night." The letter draws attention to the bereavement in 2013 and to ZZ's loneliness and ends with an indication that N1 will have to go to ASC to withdraw help (except for a Sunday visit) for financial reasons if the claim to the Department for Work and Pensions is unsuccessful. The GP IMR states that the letter did not raise clinical concerns (the letter did not but the copy of the letter to the Department of Work and Pensions attached to it did). The GP practice IMR more generally states: "There were no concerns in respect of her ability to look after herself, either from paid carers or relatives. Indeed her relatives wrote to the practice to express the view that ZZ did not wish for contact with medical carers". In fact the letter from N1 to the GP said: "Between you and myself – I don't think she needs a Doctor she is in good spirits, when I mention why a doctor hasn't been in touch she gets a bit panicky and says she doesn't need a doctor she is fine....I leave the subject – I think it's an age thing she has a slight fear of Doctors (I'm sure this is common in elderly people)". He says that he attached the letter for information and that the practice may be asked to support the claim. This was very much a missed opportunity to pick up on the pressure that N1 was under, to note the risk factors present for ZZ and to communicate with other professionals in respect of those factors.
- 6.3.25. In respect of ZZ's resistance to personal care there is no record of any conversation with ZZ about this. Near to the end of her life there is a poignant description of her clutching her blanket up under her chin. Earlier there are repeated references to her being covered on the sofa with a blanket. The research on self-neglect<sup>3</sup> offers possible explanations for such resistance: "fear, anxiety, embarrassment and shame ...were sometimes present"...."It is thus important that practitioners approach situations of self-neglect in ways that seek to understand this complex mix of factors, and fully consider mental health, physical health and relationships within a holistic assessment". Such practice in respect of assessment and conversation was absent in the case of ZZ.

- 6.3.26. The research<sup>3</sup> sheds some light on the importance of what it refers to as “concerned curiosity .... A key element in the emotional response of many was their perception of how they would be perceived by other people [and consequent reluctance to let people see the mess they were in]”. Despite ZZ’s resistance it cannot be ruled out that she might have welcomed firm but sensitive challenge: the research describes “one woman communicated what might appear to be a contrasting anxiety in her interview. Rather than fear of being found out, one of her concerns was that she was perhaps only too capable of covering up the extent of her self-neglect and people (primarily professionals, workers, or service managers) therefore did not realise how badly it was affecting her: “I wonder if [...] everybody thinks I’m okay, but I’m not okay – I’m very, very not okay”.”
- 6.3.27. The responsibility for engaging with the individual at this level rests with *all* agencies and staff. The individual who is resistant to engaging will select the practitioner with whom they feel able to confide. All need to be alert to opportunities to engage if they present. *Making Safeguarding Personal* is a core principle set out in the Care and Support Statutory Guidance (Department of Health (DH): October 2014) which states: “Making safeguarding personal means it should be person-led and outcome-focused. It engages the person in a conversation about how best to respond to their safeguarding situation in a way that enhances involvement, choice and control as well as improving quality of life, wellbeing and safety. Nevertheless, there are key issues that local authorities and their partners should consider ...if they suspect or are made aware of abuse or neglect”. “We all have different preferences, histories, circumstances and life-styles, so it is unhelpful to prescribe a process that must be followed whenever a concern is raised”. The Care Act 2014 recognises the need to engage at an individual and personal level but at the same time recognising that alongside respecting choice are considerations of safety and the need to consider a range of key issues”. SAPB engagement as a whole partnership in Camden with *Making Safeguarding Personal* will support improvement.

#### 6.4. **Assessment, care planning and review**

- 6.4.1. These aspects of practice are essential foundations for effective work with the risk inherent in ZZ’s situation. There were clear flaws in practice in this context. There must be a focus on addressing the specifics in respect of need and risk in the assessment and care plan and on the extent to which the care plan is addressing those identified needs/ risks on review. Inconsistencies, inaccuracies and incompleteness in assessments/ reviews as well as a lack of detail and specificity made it very difficult to either identify or to track and manage the level of need and risk alongside ZZ.
- 6.4.2. The first ASC assessment (December 2011) contained very little information. There were simply basic factual details (name, address etc.). The support plan was to meet the following outcomes:
- “To provide support and assistance with personal care and domestic tasks while carer is in hospital
  - To ensure ZZ’s personal hygiene is maintained
  - To ensure adequate nutrition intake as ZZ is unable to prepare any meal.”

The care plan was set out as in paragraph 5.4 (above). It noted that ZZ: “suffers with nervous anxiety which makes her shaky ...she has been housebound for years as she doesn’t like open spaces” and referred to poor mobility and that the neighbour, NB2, was helping with shopping and finances. It referred in error to her ‘husband’ being in hospital.

6.4.3. The above was an urgent request for home care and some mitigation for a scant assessment. However this made depth and quality of the first review the more important. This is recorded in paragraph 5.9 (above) and was conducted by SW1 through a home visit on 22<sup>nd</sup> December 2011, 17 days after the emergency home care package was put in place.

6.4.4. In response to a question from the SCR panel about this assessment ASC acknowledged that this first review after initial assessment was inadequate, stating that: “As a result of the visit, it was identified that there was insufficient time in the home care package for the worker to prepare the evening meal, and the evening visit was temporarily increased by 15 minutes until a microwave could be purchased. This change to the home care package was recorded in the case notes”. There is not a formal review document on file. Therefore, it is likely that, as for later reviews, ZZ confirmed that the care package was meeting her needs and that the review did not specifically explore individual risks or outcomes. ASC acknowledges that “it is not clear from the records whether the assessor deliberately used the case notes to record the home visit and the outcome (amended home care package) in lieu of a full review document, or whether the lack of a review document was an oversight on her part.....the records are inadequate to establish what was discussed in the review visit. This is further evidence of the poor quality of the review and recording, although it is clear from the records that a face-to-face review was undertaken with a home visit, and that it resulted in an amendment to the care plan”.

6.4.5. In May 2012 a further ASC assessment took place. Details of the assessment and the associated support plan are recorded in paragraphs 5.21 and 5.22 (above). Information recorded in respect of ZZ and the care plan included:

- “She is only able to wash her face and she is using a commode which needs help emptying it”
- “She is unable to stand for more than a couple of minutes”
- “She is at risk of falls”
- “Risk of malnutrition, falls and self-neglect” ....”In order to manage above risks ZZ needs to be assisted with personal care and meals preparation”
- ZZ “suffers with nervous anxiety which makes her shaky ...she has been housebound for years as she doesn’t like open spaces”.

It recorded that there was no support network apart from neighbours. (This failed to recognise the contribution of ZZ’s nephew).

6.4.6. The support plan at this time included: carers assist with strip wash; get dressed; empty commode; prepare breakfast (and that if ZZ refused breakfast it should be left for her to eat later on); prepare lunch and assist with personal care if needed. In the evening meal preparation and personal care if required.

6.4.7. The ASC IMR acknowledges in respect of assessment, support planning and review that “There is a general sense that it was fairly rushed, and a tick-box exercise to get a care package in place with minimal work.....There was not a

clear chain of logic ...which clearly itemises and links ZZ's needs, risks, support plan, outcomes and reviews, to ensure that each need and risk is properly carried through".

- 6.4.8. On 14<sup>th</sup> August 2012 a home visit was undertaken by SW1. The quality of the review is poor. It repeats exactly the information as in previous assessments. It gives identified risks as: malnutrition, falls and self-neglect and that these are being managed through the provision of a care package. Despite this information the review concludes that there are "no outstanding issues identified or reported. Case to be transferred to yearly review". The case file note is set out in paragraph 5.25 (above) and conveys that SW1 visited for the purpose of closing this case and that any conversation was extremely superficial. There was little attempt to review how things were from ZZ's perspective.
- 6.4.9. The final support plan review by ASC took place in July 2013. This is set out in paragraphs 6.3.16 and in 5.37 (above). The lack of anything more than superficial inquiry into presenting issues was problematic. In respect of concerns expressed by carer 1 about the absence of bereavement support and ZZ's sedentary lifestyle and lack of inclination to take steps to address these issues SW2 assessed that, as ZZ had capacity and "appeared physically well" and had said she would seek support if required, then there was nothing in addition to the existing care plan that could or should be done. Despite the previous reviews having identified risks of: malnutrition, falls and self-neglect, this review stated ZZ "is not a risk to herself or others".
- 6.4.10. Despite significant risks (articulated in the July 2013 ASC review as malnutrition; falls; self-neglect) as well as a range of unexplored and unresolved issues the case of ZZ was transferred for annual review only. Research and learning from such cases of self-neglect indicate that such a decision would be inadvisable....there is a need to "keep the door open" in case of moments of motivation or willingness to engage. Furthermore it is doubtful that any of the other agencies involved understood that this was the case.
- 6.4.11. Communication between the commissioner of the care service for ZZ and the provider was very poor. The presence of the carer 1 at this last review in July was not a planned step (in the sense that it is good practice to involve front line carers in reviews), but happened as a result of ZZ saying that she would be unable to let SW2 in and therefore they would need to visit whilst the carer was there. It is remarkable that both with this July review and the one in May 2012 PC were unaware that this had taken place (see paragraphs 5.22 and 5.37 above) even though the carer was there. The council acknowledged in April 2014 the "resource intensive" nature of reviews and the need to prioritise. This context of scarcity of resources and rationing of services is a significant backdrop against which the findings of this review must be seen and is a national issue.
- 6.4.12. There must be clear expectations of commissioners and providers once a care plan is in place setting out when communication is necessary and for what purpose. If something is varied from the initial care plan then this requires communication/ discussion. If particular issues/ risks emerge these must be discussed. For example, it is picked up in both the reports of PC and ASC for this review that the death of ZZ's partner should have triggered a review. A

review should have been requested immediately too by PC when concerns about ZZ escalated. Carers should know and be confident that as soon as there are any restrictions on them being able to carry out the care plan, this should be reported. If it implies an inability to meet the outcomes and needs and mitigate the risks set out in care plans then a review is indicated. Even when carer 1 did report concerns, albeit very late in the day, the response from the team leader on 5<sup>th</sup> June 2014 lacked any real sense of urgency. The responsibility of the organisation as well as the individual carer is underlined here.

- 6.4.13. The service provider, PC, carried out its own assessments and reviews in accordance with its own procedures. Initial assessments were carried out on 9<sup>th</sup> December 2011 within the timescales set down following referral from the commissioner. This is noted in paragraph 5.6 (above). The manual handling risk assessment noted that ZZ had tripped on a carpet during the previous year and “cannot weight bear with limited upper body strength”. ZZ is reported to have said that she did not need help to stand. On the standard form where equipment is referred to the entry is simply “n/a”. There was no communication in either direction between commissioner and provider when reviews were carried out nor was there any communication when the need for referral to other professionals was clearly indicated. Neither the care provider nor the social workers thought to instigate a discussion and referral in the light of a clear indication from the assessments that an occupational therapy assessment would be advisable (given the severe limitations on ZZ’s abilities to carry out activities of daily living).
- 6.4.14. The failure of either ASC or PC to recognise the benefits that referrals to other appropriate professionals might bring to the situation and the failure to discuss this with ZZ is significant. In the light of needs and risks indicated referrals should have been made to an occupational therapist; district nurse; tissue viability nurse; and dietician at the very least with indications too that referral to a mental health professional or psychologist would be advisable. This was symptomatic of a lack of holistic assessment and attention only to the immediate presenting issues (partner in hospital and ZZ’s inability to make food etc.). This issue is identified in the ASC IMR: “Given the complexity of ZZ’s needs, including agoraphobia, unsuitable housing, anxiety and substantially reduced mobility, it is likely that a multi-disciplinary assessment may have made a significant difference to ZZ’s overall wellbeing”.
- 6.4.15. There was at no point a drawing together of all of the available information and insights into a holistic, multi-disciplinary assessment and needs analysis. Had this been attempted with records from housing, GP, and ASC brought together a picture of someone requiring a more proactive and preventive approach might have emerged. The necessity for engagement of a range of professionals would have been clear.
- 6.4.16. For example, mental health issues were known to be a significant issue for ZZ by both the GP and housing. We know from historical GP and housing records that ZZ had longstanding psychological problems (anxiety, depression, agoraphobia, and associated consequences of loss/ bereavement). She had been offered the support of a psychiatrist in the 1980s with whom she had failed to keep appointments. There are no recorded subsequent attempts to offer such support. A recent report underlines the prevalence and the significance of



mental health issues affecting older people in receipt of domiciliary care<sup>4</sup>: “Commissioners and service providers need to seek and exploit opportunities for joint working and service delivery that can address both physical and mental health needs”. The above report highlights the poor access older people have to treatment for disorders such as anxiety and depression and highlights the impact of both mental and physical difficulties on individuals’ ability to care for themselves. The report states that “surveys indicate that 25% of people receiving home care services are depressed”. This indicates not only the necessity to facilitate access to therapies/ treatment but also the need to highlight in training for domiciliary care workers the very significant impact of mental health issues on the ability of the individual to look after their own health, by taking a good diet, keeping active both mentally and physically, managing medication correctly and co-operating with treatment. These are all issues and concerns that needed to be taken on board by those working with ZZ. However the significance of these remained unidentified.

- 6.4.17. The medications management assessment by PC on 9<sup>th</sup> December 2011 recorded that ZZ was able to take her own medication. It indicated that she felt that the medication was effective, that ZZ remembered to take her medication and understand the directions for doing so and what the medications were for. It indicated that there were no “critical elements” to the medication. And that ZZ was independent in this respect. There is no indication that any problem was subsequently identified. Communication with ZZ’s nephew might have uncovered ZZ’s lack of compliance in this respect.
- 6.4.18. The ASC IMR states that liaison with the GP “may have identified any medication that ZZ was on, so that more specific care and support planning could be provided around monitoring of medication self-administration and monitoring of deterioration in any medical conditions or health risks”. There was no such connection with the GP on this issue and no monitoring of ZZ’s compliance despite unopened medication in evidence in the flat. A medication review is triggered by the GP practice when medication is requested. Because ZZ stopped taking or requesting repeat medication the review in 2014 was not triggered. This is an issue that the practice is seeking to resolve through its own action plan in response to the case of ZZ.
- 6.4.19. Within PC, reviews were carried out annually as set down in their procedure. Quality monitoring visits and telephone interviews with ZZ were carried out in the interim. These are recorded in paragraphs 5.14; 5.29; 5.30; and 5.45 (above). The nature of these reviews was in common with those of ASC: superficial with only scant information. In 2012 “no change “was recorded and that ZZ was pleased with the service. In 2013 the same was recorded and a manual handling review noted ZZ as: housebound; not weight bearing and limited upper body strength; sleeping on the sofa; and carer assisting with a strip wash. In 2014 again no change was recorded and ZZ’s satisfaction with the service was indicated. The same needs were noted as in the manual handling assessment of 2013, except that ZZ is recorded as “able to transfer onto the commode”. This is surprising given the lack of ability to weight bear and the upper body strength issues, and again it is surprising that this does not result in a conversation with ASC about possible referral for OT assessment.

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<sup>4</sup> Joint Commissioning Panel for Mental Health, (2013). “[Guidance for Commissioners of Older People’s Mental Health Services.](#)” London: JCP-MH

- 6.4.20. The PC action plan in respect of the learning from this case talks of the need for review to look at all of the issues/ elements that are known to be relevant or a cause for concern, such as nutrition and hygiene, rather than just asking and accepting whether the individual is “happy”. It needs to reflect clarity about each relevant need and risk and the extent to which the care plan is meeting/ mitigating these. This was not the case.
- 6.4.21. Reviews were undertaken within the timescales set down but despite them seemingly complying with procedures, these failed across provider and commissioner to pick up on the fact that the care plan was not able to be delivered and that the risks were both present and escalating. The assessments and reviews failed to seek any clarification from each other or from elsewhere (relatives, GP, housing) about the known concerns or to seek the support of specialist professionals when there were known issues necessitating such referral for specialist support.
- 6.4.22. The processes for formal assessments and reviews were superficially in place at PC, perhaps masking the reality of a lack of robustness when inspections took place in 2012/ 2013. Records were complete, and completed at the right intervals by PC, but they were ineffective in picking up on the central concerns. We know now from interviews since the death of ZZ that the checking of daily logs by supervising staff at PC was rarely taking place. This important check against what was said at reviews was almost completely absent. This would have introduced a way of checking on a regular basis whether the constant refrain of “all OK” and “all fine” from carers and from ZZ bore any resemblance to the reality. This was a serious failing. The excerpts from daily logs set out in section 5 give examples showing accumulating concerns, especially in 2014.
- 6.4.23. PC acknowledges these issues and has put in place an improved review process and, in addition, PC acknowledges the importance of information in the daily logs for reviewing on a continual basis. PC is introducing technology to enable immediate passing of daily information from carers to the office. It must be noted however that in the case of ZZ the supervisory staff acknowledged that they had not read the daily logs due to pressure on time. The June 2014 CQC inspection uncovered too few supervisory or front line staff. This issue will need to be addressed if these measures are to be robustly carried through in day to day practice.
- 6.4.24. The failings in basic practice in assessing, monitoring and reviewing needs and risks outlined above, alongside the failures set out in section 6.2 (above) in relation to establishing any kind of relationship with ZZ, led to neither the provider nor the commissioner identifying, acknowledging or addressing the serious level of deterioration in ZZ’s condition. Neither did they identify ZZ’s needs in a sufficiently specific way to highlight that they needed to enlist the support of other professionals so that all of ZZ’s need could be addressed.

***What are the elements of a good multi-disciplinary assessment?***

- 6.4.25. Whilst the issue of NHS Continuing Healthcare is not one that arose in the case of ZZ, the following advice on assessment from this guidance is more broadly applicable. It offers constructive advice for addressing the issues reflected by the evidence given in this section of the review.

6.4.26. The national framework on NHS Continuing Healthcare 2012<sup>5</sup> practice guidance identifies elements of a quality multi-disciplinary assessment of an individual's health and social care needs including:

- “person-centred, making sure that the individual and their representative(s) are fully involved, that their views and aspirations are reflected and that their abilities as well as their difficulties are considered;
- informed by information from those directly caring for the individual (whether paid or unpaid);
- holistic, looking at the range of their needs from different professional and personal viewpoints, and considering how different needs interact;
- taking into account differing professional views and reaching a commonly agreed conclusion;
- considerate of the impact of the individual's needs on others;
- focussed on improved outcomes for the individual;
- evidence-based – providing objective evidence for any subjective judgements made [*such as “she is happy”; “all OK”*];
- clear about needs requiring support in order to inform the commissioning of an appropriate care package; and
- clear about the degree and nature of any risks to the individual (or others), the individual's view on these, and how best to manage the risks”.

This will be helpful guidance to underline in addressing the shortcomings in this respect in Camden. Support and evidence of its robust adoption in practice forms part of the recommendations of this report. These principles are in line with the guidance on assessment in the Care and Support Statutory guidance (DH: 2014), issued under the Care Act 2014.

6.4.27. The need to enhance practice in reviewing needs and risks is clear in the above examples from reviews in the case of ZZ. The Guidance on Eligibility Criteria for Adult Social Care offers helpful advice in this respect which all agencies must take on board.<sup>6</sup> The guidance issued would suggest that, in the context of risk, reviews should:

- Establish the extent to which the risks identified in the risk assessment are being reduced via the arrangements set out in the action plan;
- Consider whether the needs and circumstances of the person and/ or their carer(s) have changed and how this impacts on the level of risk;
- Support people to themselves review the risk decisions and how arrangements to manage the risks might need to be amended over time;
- Demonstrate a partnership approach across agencies and with the service user as well as their family and friends if they choose;
- Ensure that the risk assessment recorded in the care plan is up to date and takes account of new information/ developments and identify any further action that needs to be taken to address issues relating to the risk;
- Support people to strengthen their informal support networks; and
- A written record of the results of these considerations should be kept and shared with the person.

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<sup>5</sup> DH, (2012). “National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care” (revised) [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213137/National-Framework-for-NHS-CHC-NHS-FNC-Nov-2012.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213137/National-Framework-for-NHS-CHC-NHS-FNC-Nov-2012.pdf)

<sup>6</sup> DH, (2010). “*Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. Guidance on Eligibility Criteria for Adult Social Care, England, 2010*”.

These features of practice would have improved effectiveness in this case.

## 6.5. Working with risk

- 6.5.1. The above flaws in practice set a foundation from which effective work with the risk inherent in ZZ's situation would have been extremely difficult. ASC acknowledged that risks "were noted in vague terms in a single line as "malnutrition, falls and self-neglect". Even with a prompt in place within the format for the July 2013 assessment, ASC recorded that ZZ was not a risk to herself or others. There was no mention, let alone a review, of the three areas of risk mentioned in previous assessments/ reviews. ASC did not track risks across the period of time under scrutiny by this review. At points in time when risks were identified and recorded the implications were not explored or managed. There is no record to indicate that the extent, nature and causes of malnourishment, falls and self-neglect were ever assessed or analysed. Indeed for key staff and professionals involved with ZZ they remained largely unidentified. Therefore plans to keep track of them or manage them were not in place. The outcomes for ZZ witness the significance of this failing.
- 6.5.2. Most risk assessment frameworks are based upon a framework which involves the gathering of information in respect of a given situation or decision and evaluation of the potential severity of **outcomes/ impacts** as well as the **likelihood/ probability** of those outcomes occurring. Based on this assessment, risk management is about using available resources to put in place an action plan to reduce the likelihood of potential harmful outcomes and to increase the probability of beneficial outcomes. Such action plans must be clear about:
- Actions required in respect of *all* identified areas of risk
  - *Who* is responsible for those actions
  - Within what *timescales*
  - *Monitoring and review* arrangements and timescales for this.
- Such a framework is far removed from the practice in the case of ZZ which never made progress on the initial step in this, which is to clearly identify each of the potential harms.
- 6.5.3. This very superficial mention in ASC records of what were highly significant risks was never a feature at all in the records of PC. Any reference to these areas of risk was even more obscure. There was reference to poor mobility and to the need to ensure adequate nutrition (and leave food for ZZ should she not wish to eat it whilst carers were present). What was more often recorded was an absence of any concern on the part of the carers (in supervision sessions). There was one isolated incident recorded in respect of risk by PC in February 2014 (see paragraph 5.49 above) where PC did report to ASC that ZZ had said that she would kill herself if carer 1 was taken away from her (due to re-commissioning process of home care services). Communication took place between ASC and PC and reassurances were offered to ZZ. There was no such communication on any ongoing areas of risk.
- 6.5.4. Risks were simply not identified by a number of key staff and professionals. The reasons for this are numerous including: lack of communication across agencies; lack of holistic view taken of ZZ; lack of engagement with ZZ; lack of awareness of risk factors for certain conditions (such as pressure ulcers); lack of

time; poor practice; lack of awareness of and understanding of issues such as capacity and consent and duty of care; and poor quality of supervision. Agencies who worked with ZZ are putting in place a range of measures to support early identification of risk. For example PC is putting in place measures to increase awareness of risks relating to pressure ulcers and to nutrition; it is supporting measures to increase the likelihood of staff identifying these issues and speaking to other relevant professionals. The GP practice action plan includes identifying and acting upon signs that would trigger a greater level of oversight by the practice and/ or a greater level of connection with other professionals, for example: repeated refusal of medication reviews, vaccinations, and blood tests where the individual is known to have a range of chronic conditions; and patients with ongoing chronic conditions who fail to request medication (anyone over 65 and or with such a condition). The practice is considering the possibility of initiating face to face contact with all older patients every 12 months perhaps via a community contact/ nurse. There is consideration too of a register of non-compliant patients to ensure review. The practice might consider the merits too of a greater level of multi-agency communication and enlisting the support of those professionals also involved with an individual in establishing the reasons for non-compliance.

- 6.5.5. All of these improvements may have an impact but simple vigilance and recording of signs of deterioration, and an awareness of and confidence in when it is appropriate to escalate such concerns, is important too. On admission to University College London Hospital ZZ weighed only 4 stones 10lbs at a height of 4ft 11inches. This is a BMI of just over 13. It is remarkable that none of her carers was aware of this significant weight loss. This vigilance must go hand in hand with named individuals taking responsibility for specific issues/ areas of risk as they emerge within care plans and protection plans.
- 6.5.6. Of central importance too is the skill of staff at all levels in having conversations with people that seek to elicit what is important to the person, what/ who is supporting them, what/ who is getting in the way from their perspective. Processes have diverted professionals and staff away from a focus on these skills to a focus on processes and filling in forms and paperwork. The supported decision tool in appendix A of DH guidance on risk<sup>7</sup> will help staff at every level to regain confidence in having those conversations.
- 6.5.7. Risks were rarely formally acknowledged and recorded and therefore plans to manage and keep track of them were lacking. There was a failure to collate information about risk into a holistic assessment in order to inform shared decisions and actions across the range of professionals and staff. Neither were professionals proactive in informing ZZ of the range of risks in order to support informed choices and to ensure that she fully understood the consequences of her lack of engagement with/ acceptance of support. People who use services need to inform, and be informed by, the risk assessment.
- 6.5.8. There was a tendency to attend to immediate support needs rather than stepping back to consider all of the potential risks that were an issue for ZZ and

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<sup>7</sup> DH, (May 2007). "Independence, choice and risk: a guide to best practice in supported decision making". [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_074773](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074773)

seeing that, as she became frailer, the impact of these and a pattern of increasing risk might be an issue. There was never a formal stand-alone risk assessment recorded nor any multi-agency meeting or communication to address the risk.

- 6.5.9. Organisations should consider too the need to bring objectivity to situations where carers work with individuals over a long period and the fact that in those circumstances the carer can fail to notice a gradual but significant decline, even where this becomes extreme. This appears to have been an issue in the case of ZZ where carer 1 only finally took her concerns to a supervisor in the PC office when a new carer, who was shadowing her as part of induction, expressed concerns.
- 6.5.10. There is local advice and guidance available to professionals and staff across all agencies in respect of working with risk as follows in paragraphs 6.5.11 to 6.5.20. Some of this would have supported/ improved practice. Guidance was available for social care staff, health staff and service providers. The local guidance would merit updating and enhancing in the light of lessons from this review.
- 6.5.11. The Camden High Risk Panel (HRP) is a consultative and advisory panel supporting work in high risk cases and specifically includes self-neglect in its remit. In cases where there is concern about the level of risk it seeks to support risk reduction by bringing to bear the knowledge, expertise and capability (ideas, potential actions, and ways of addressing particular situations) of a range of organisations.
- 6.5.12. The panel hears cases and proposes actions and a multiagency lead. Some of the outcomes it achieves include:
- For residents:
- Joint home visits
  - Access to experts, services and support not previously available.
- For professionals:
- Validation of workers' involvement and actions to date
  - New networks – knowing who to contact for what
  - More action taken “off-line”
  - Accessing law/ powers/ duties e.g. powers of entry, tenancy non-compliance
  - Case resolution.
- 6.5.13. Its core principles are:
- Any agency can refer and present a case
  - Panel seeks clarification, shares information, and offers challenge/ support
  - Panel considers intervention options, including legal powers and duties; vulnerability/equality issues; need for step-up to safeguarding
  - Panel agrees actions and allocated lead to progress case via “business as usual”
  - Cases do not usually return to panel.

- 6.5.14. According to the local protocol the HRP hears six – eight cases which are each presented and discussed in 15 minutes. Actions are required within five days. This time allowed for each case is short given the complexities of what is being dealt with. There is 15 minutes at the beginning of each meeting to share learning from the previous meeting's cases. This has been recognised to an extent in practice since the HRP currently deals with significantly fewer cases at each meeting, offering around 30 minutes for discussion of each case.
- 6.5.15. The HRP is a very positive step. There would be merit in developing this drawing on the lessons from this SCR. The HRP should consider the following:
- The current membership does not include general practice/ district nursing/ tissue viability nurses/ dieticians. This needs to be considered. It does include others who might have offered a helpful perspective: mental health; housing; psychology; and ASC.
  - It does have a learning perspective but this is a brief input of 15 minutes at the beginning of each meeting for the learning from six – eight cases. It is worth considering that for situations involving issues such as hoarding and self-neglect the issues are complex and will require more time. (This additional time is already beginning to be allocated but this needs to be set out as a general principle). The panel should consider how it will extract and disseminate the learning and identify where this needs to reach front line staff and how this can be achieved.
  - The HRP states that it has a consultative and advisory role only. This is in respect of particular cases brought to the panel. The HRP might consider a broader role in advising on recurrent issues and highlighting policy/ guidance vacuums. It might link with procurement and the provider forums.
  - The time given for each case presentation and discussion again does not lend itself to cases such as those involving self-neglect where the discussion will need to be more detailed and deal with complex issues. The recognition of this needs to be formalised.
- 6.5.16. Camden ASC has in place a High Risk/ Complex Cases Policy, Procedure and Guidance (2013) and a risk assessment template. This is due for review. The policy/ guidance refers to the HRP and includes in its scope situations of self-neglect and where people decline support (“service refusers/ non-engagers”). It states: “Where support is offered and refused, all other options should be explored to engage the high risk person, including legal enforcement measures (if applicable). If there is no legal ground for the person to accept support, it is vital to note this in the case records as it may be crucial information at a later date. These cases can be referred to the HRP for advice and guidance”. The aims and objectives of the policy appear almost coterminous with those of the HRP.
- 6.5.17. The guidance advises: “It is important to note that it is good practice to signpost and support people even if they have the capacity to make that specific decision”. There is a “limited” table of possible legal responses. It states that mental capacity issues can be problematic and underlines the five core principles of the Mental Capacity Act 2005 (MCA). In respect of interventions it states “it is extremely important to develop a good relationship with the high risk person in order to effectively support them. Working alongside their existing support networks can alleviate notions of mistrust and can be a gateway to



providing further support". The policy promotes multi-agency engagement to address presenting issues.

6.5.18. This policy and guidance highlights some of the key issues for consideration but it doesn't go far enough in offering support and direction with the complex issues that present in high risk cases such as that of ZZ. Guidance is needed that will support the whole partnership and which draws on the key learning points raised under the headline issues raised within this review report. This needs to be underpinned with a range of learning and development opportunities.

6.5.19. Support should also be available to staff from local safeguarding policies and related learning and development opportunities. However, these policies will need to be reviewed to ensure that there is sufficient focus on identifying and mitigating risk in the context of neglect and self-neglect. It is noticeable that there is little focus on this in the PC policy (although it is mentioned under "types of abuse"). It is one of the most challenging areas of safeguarding practice and merits greater attention.

6.5.20. Policy and practice in risk work must be underpinned by a knowledge of and ability to apply the legislation in practice. The law can support service users, staff and organisations in working with risk. This is explored further in section 6.7 below.

6.5.21. **Commissioning of services** has a crucial role in underlining the importance of robust multi-agency working within situations of risk. Regulations, contracts and service specifications can and do underline these issues and must be robustly monitored. The CQC guidance about compliance<sup>8</sup> was designed to help providers comply with the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010<sup>9</sup>. It states in respect of regulation 24, outcome 6 that service provision in relation to multi-agency work in situations involving risk "Will lead effectively to manage risk (outcome 6) so that people who use services can be confident that when more than one service, team, individual or agency is involved at the same time in their care, treatment and support, or are planned to be in the future, the services provided are organised so that:

- All those involved understand which service has the coordinating role and *who is responsible for each element of care, treatment and support* to be delivered.
- Each service, team, individual or agency is involved when the plan of care is reviewed or brought up to date.
- Where appropriate all those involved discuss together the plan of care for the person who uses services."

This is important for the regulator to focus on and that in monitoring contracts such aspects of regulatory requirements are monitored. This begins with clarity as to roles and responsibilities and required actions (and what to do if this needs to change).

## 6.6. Risk of pressure ulcers

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<sup>8</sup> CQC, (March 2010). "Essential standards of quality and safety".

<sup>9</sup> [http://www.cqc.org.uk/sites/default/files/documents/gac\\_-\\_dec\\_2011\\_update.pdf](http://www.cqc.org.uk/sites/default/files/documents/gac_-_dec_2011_update.pdf)



- 6.6.1. On the day before ZZ died she was admitted to University College London Hospital with 13 pressure ulcers at various sites across her body including hands, feet, chest, sacrum and legs. Nine of these were grade four and bones/tissue were visible in places. ZZ presented for some considerable time with clear risk factors in relation to pressure ulcers. She was immobile; she sat or lay in one place all day and night; there were personal hygiene issues; her nutrition intake was inadequate. It is unclear as to whether her liquid intake was sufficient in general but certainly in the last few days of her life it was clear that she was not taking in sufficient fluid. This culminated by 8<sup>th</sup> June 2014 in her not passing urine. National guidelines<sup>6</sup> state: “Adequate hydration and nutritional intakes of, energy, protein, carbohydrate and micronutrients (vitamins and minerals) are all associated with skin integrity and the prevention of tissue breakdown. It is commonly considered that the development of pressure ulcers can be associated with an inadequate nutritional intake. Those who are underweight, immobile, overweight or obese are also considered as being at increased risk of developing pressure ulcers”.
- 6.6.2. Guidance on the prevention and management of pressure ulcers is readily available and all of this advocates engagement with patients and carers. The National Institute for Health and Care Excellence (NICE) guidelines<sup>10</sup> state “Patients should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals”. The issue in the case of ZZ was of identification of the risk so that the right professionals would have been involved and able to advise both ZZ and carers.
- 6.6.3. Despite the range of risk factors in relation to pressure ulcers and a specific phone call to the GP in February 2012 in respect of a “red blotch” on her hip and a request for cream, there was no proactive involvement or any assessment of the risk of pressure ulcers. In the PC response to a question from the panel about level of training and awareness in respect of pressure ulcers, the response included: “carer 2 had a good awareness of pressure sores and of identifying risk. If she had noticed the pressure sores she knew how to respond, but she says she was not aware of them”. Awareness of the risk factors was a key issue. The carer may not have seen pressure ulcers but they should have been aware of the indicators of risk.
- 6.6.4. Guidelines issued by the NICE<sup>10</sup> state that all healthcare professionals are expected to take NICE clinical guidelines fully into account when exercising their clinical judgement. These are made available to staff at University College London Hospital. The guidelines recommend that healthcare professionals must:
- “Be aware that all patients are potentially at risk of developing a pressure ulcer.”
  - “Carry out and document an assessment of pressure ulcer risk for adults.... If they have a risk factor for example: significantly limited mobility-significant loss of sensation; a previous or current pressure ulcer; nutritional deficiency; the inability to reposition themselves; significant cognitive impairment.”

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<sup>10</sup> NICE, (April, 2014). [“Pressure ulcers: prevention and management of pressure ulcers”](#). NICE clinical guideline 179.

Consideration is recommended of using a validated scale to support clinical judgement (for example, the Braden scale, the Waterlow<sup>11</sup> score or the Norton risk-assessment scale) when assessing pressure ulcer risk.

6.6.5. Some of the recommendations in the above guidance are particularly pertinent in the case of ZZ for example:

“Encourage adults who have been assessed as being at risk of developing a pressure ulcer to change their position frequently... If they are unable to reposition themselves, offer help to do so, using appropriate equipment if needed.”

Consider pressure relieving/ redistributing devices: The devices used include different types of mattresses, overlays, cushions and seating.

“Offer timely, tailored information to people who have been assessed as being at high risk of developing a pressure ulcer, and their carers. Include:

- the causes of a pressure ulcer
- the early signs of a pressure ulcer
- ways to prevent a pressure ulcer
- the implications of having a pressure ulcer.”

“Nutritional supplements and hydration:

- Offer adults with a pressure ulcer a nutritional assessment by a dietician or other healthcare professional with the necessary skills and competencies.
- Offer nutritional supplements to adults with a pressure ulcer who have a nutritional deficiency.”

6.6.6. Recommendations on the training and education of healthcare professionals are given:

“Provide training to healthcare professionals on preventing a pressure ulcer, including:

- who is most likely to be at risk of developing a pressure ulcer
- how to identify pressure damage
- what steps to take to prevent new or further pressure damage
- who to contact for further information and for further action.”

6.6.7. This might be recommended training for domiciliary carers too. The NVQ Level 3 Diploma in Health and Social Care does not make this mandatory training although it does include non-mandatory modules on:

- Undertake agreed pressure area care
- Undertake tissue viability risk assessments.

6.6.8. NICE has also produced guidance for patients covering these issues.

6.6.9. Whilst these guidelines were made available shortly before ZZ died the principles that were central in the case of ZZ were well known. For example,

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<sup>11</sup> <http://www.judy-waterlow.co.uk/downloads/Waterlow%20Score%20Card-front.pdf>  
<http://www.judy-waterlow.co.uk/downloads/Waterlow%20Score%20Card-back.pdf>

Royal College of Nursing (RCN) guidelines from 2005<sup>12</sup> advocate a collaborative multi-agency approach to pressure ulcer care. They refer too to the need for person-centred care to involve and include patients and carers in decision making and in management of pressure ulcers: carers and patients should be informed as to potential risks/ complications and when and how to seek help. There is specific guidance available from this source to give to carers and to service users.

6.6.10. The Royal Borough of Kensington and Chelsea Multi-agency Pressure Ulcer Protocol gives some clear guidance on identification of pressure ulcers and the necessary steps for effective prevention and management. This includes advice that:

- A person's risk of developing pressure ulcers should be assessed and documented. Re-assessment frequency will reflect the context: a change in the person's condition would indicate earlier re-assessment.
- An appropriate plan of care including skin, wound care, repositioning and pressure relieving surfaces/ devices should be set as appropriate to the person's need.

The protocol indicates that if there is no such assessment or care planning then neglect might be indicated where pressure ulcers are present and this must be considered under safeguarding procedures. This guidance is informing local guidance elsewhere across London. In Camden it was adopted in 2014/15 and is currently being implemented across health providers and care homes, led by Camden Clinical Commissioning Group. The protocol refers, where the patient has capacity (as in the case of ZZ), to the need to ensure that the patient has information about the risks of being non-compliant. It says, "If they have capacity they are within their rights not to do so, however the person should have been informed of the risk and been supported to make an informed decision". This was a significant omission in the case of ZZ.

6.6.11. Guidance elsewhere underlines the need to empower patients and carers to be assertive in ensuring their skin and pressure ulcer care needs are met and ensuring patient/ carer access to educational materials and protocols and access to a point of expert contact for support if they have concerns. They need to know who to go to for advice and support and when this might be necessary. This is underlined locally. The University College London Hospital guidance on pressure ulcers "Guidelines for the SSKIN Care Bundle" (December 2014) underlines the need to involve and empower patients and carers through information and advice. The guidance advocates openness with patients about the fact that they have been identified as being at risk of pressure ulcer development and the need to explain interventions and key issues and principles.

6.6.12. PC, the care provider for ZZ, has since the death of ZZ provided information from this guidance to all staff.

6.6.13. An overview of the available advice and literature highlights the following as important in the prevention and management of pressure ulcers:

- Importance of the principles of the MCA as well as principles of duty of care (exploration of issues of consent, capacity and best interests)

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<sup>12</sup> RCN, (2005). "[The management of pressure ulcers in primary and secondary care: a clinical practice guideline.](#)"

- Engagement of carers (paid and unpaid) and relatives
- Risk assessment should be undertaken swiftly at the first sign of pressure ulcers and be ongoing
- Ongoing care for those at risk who should receive a level of care dependent upon the level of risk
- Expert advice must be sought to inform the care plan
- This should include recording the frequency of pressure area care required/ skin care regime and the type of pressure relieving equipment required
- There should be a focus on maintaining skin integrity and wound healing interventions where necessary
- Interventions and management must include satisfactory maintenance/ referral/ management of nutrition and hydration, hygiene, continence care and maintaining mobility
- Accurate recording of assessments, care and treatment plans and appropriate information sharing across agencies
- Consideration of provision of specialist equipment in a timely manner and appropriate advice and support in place so that it is used appropriately
- Careful attention to care needs in connection with hygiene, continence, hydration, nutrition, medications is essential.

These measures could have made a very significant difference for ZZ.

6.6.14. One of the key features of a risk assessment and a plan to manage those risks for ZZ should have been in relation to pressure ulcers. There was a reference to skin damage as early as December 2011. With the associated risk factors evident this should have resulted in a full assessment by a trained nurse. The assessment of pressure ulcer risk needed to draw on related issues such as nutrition/ weight (which was clearly an issue at least later on in the chronology). This was not evident in records. There was never a formal assessment, such as a Waterlow assessment.

## 6.7. Working with self-neglect and people who decline services/ support

6.7.1. The most recent research<sup>3</sup> defines self-neglect as follows: “Self-neglect for definitional purposes then includes both adults with and without capacity, and centres on:

- lack of self-care – neglect of personal hygiene, nutrition, hydration, and/ or health, thereby endangering safety and wellbeing, and/ or
- lack of care of one’s environment – squalor and hoarding, in the context of refusal of services that would mitigate risk of harm.

6.7.2. Certainly ZZ presented within this definition. In fact one illustration used in offering guidance within that research might almost have been referring to ZZ. It underlines the importance and the challenges of skilled practice and interaction with individuals who are self-neglecting: “This work...requires skilled interviewing and authoritative but respectful challenge rooted in concerned curiosity... *There are times when you have to weigh somebody and you have to check what their nutritional status is, it’s no good when somebody’s just lying with a sheet up to their neck all the time, to accept that what’s being said is actually true. It’s about challenging – it’s difficult, very difficult to do.*”<sup>3</sup>

- 6.7.3. Available guidance in this challenging area of practice would have supported practice. The most recent research<sup>3</sup> suggests that the challenges and the areas of practice that require attention include:
- where an individual (with mental capacity to do so) refuses services; the ethical dilemmas and fine balance required between autonomy and safety (duty of care)
  - clarity in understanding of legal options and framework
  - knowing who should be involved, who should have lead responsibility; shared ownership and co-ordination of effort
  - working with risk
  - the investment of time required and systems and structures that mitigate against this.
- 6.7.4. The challenges in respect of aspects of practice outlined in sections 6.3 – 6.6 (above), as well as issues around practice in the context of mental capacity and legal literacy (see section 6.8 below), all converge under the single heading of self-neglect. They all have a part to play in our understanding of and intervention in such situations. If an individual declines support then all of these will be important considerations:
- A risk assessment must be carried out to determine the level of seriousness of each identified risk
  - Intervention must be person-centred, understanding the individual and their context and involving them as far as possible in understanding the risk assessment and the alternatives for managing the risk
  - Information should be shared with other relevant professionals who may have a contribution to make in managing or monitoring the risks
  - Consideration must be given to the mental capacity of the individual and whether they require support in their decision making or, following an assessment that the individual lacks capacity, whether a best interests decision might be appropriate.
- 6.7.5. There was a pattern of identifiable instances where ZZ refused services (see table 2 below). Alongside these recorded and acknowledged episodes of service refusal we know now that there was a steadily declining pattern of accepting personal care and food from PC carers. This pattern of slow decline in acceptance of personal care might have been more readily identified had assessments and multi-agency working been sufficiently robust to pull all of this available information together. Set alongside this ZZ did, after some initial reluctance, accept carers calling on her three times each day. However care and support was very much on her terms. ZZ also accepted social worker visits for assessments/ reviews. Where there is such acceptance it is important to sustain the involvement of these professionals/ staff so that any opportunities that demonstrate motivation on the part of the individual can be exploited. However, the continuity which would have been important in supporting someone like ZZ who was self-neglecting was not facilitated. On 14<sup>th</sup> August 2012 SW1 carried out a home visit stating that, as ZZ's care needs were stable, he would be closing the case.

**Table 2:**

<b>Date</b>	<b>Indication of or record of refusal of service/ support</b>	<b>Significant concurrent events</b>
December	References in care plan to contingency	P2 was admitted to

2011	"if ZZ refuses to have breakfast".	hospital.
19 <sup>th</sup> January 2011	Declined GP visit when she had diarrhoea.	
Throughout early 2012	Refusal of access for essential work to be done on radiators/ heating system. This affecting neighbouring property.	
April 2012		P2 discharged from hospital.
17 <sup>th</sup> October 2012	Refusal of flu vaccination.	
22 <sup>nd</sup> October 2012	Refusal of GP review: blood tests; blood pressure check;.	
22 <sup>nd</sup> January 2013	Refusal of flu vaccination	
April 2013		P2 admitted to hospital
22 <sup>nd</sup> May 2013		P2 died
17 <sup>th</sup> August 2013	ZZ didn't want anything to eat.	
30 <sup>th</sup> October 2013	Refusal of vaccination for flu; herpes; pneumococcal.	
January 2014	It is reported by PC that ZZ refused the offer of a bed from ASC (this is not recorded in ASC chronology).	
1 <sup>st</sup> March 2014	ZZ unwell and refusing to call a doctor.	
5 <sup>th</sup> June 2014	Carer visit to office in which she reports that ZZ "refusing all personal care saying she would do it later". Carer unable to tell supervisor the date on which ZZ started to refuse. Log entries for May/ June do not reflect this.	
5 <sup>th</sup> - 9 <sup>th</sup> June 2014	ZZ not eating or agreeing to personal care.	
9 <sup>th</sup> June	Refusal of ambulance to take her to hospital.	

Prior to the period under scrutiny too there were indications from housing records of reluctance to accept support.

- 6.7.6. There is one occasion (19<sup>th</sup> February 2012) recorded where ZZ appears to have been proactive in reporting a "red blotch" on her hip to a GP and requesting cream. She was informed to contact the practice if it was not healing. It is not clear whether ZZ initiated the call.
- 6.7.7. A number of themes, which are highly pertinent to the learning from the situation involving ZZ, emerge from in-depth interviews [with managers, practitioners and people who use services] in the research on self-neglect:<sup>3</sup>
- "care management models that restrict the time and focus of the practitioner did not provide the structure in which such work can be done"
  - "the importance of relationship in securing engagement and achieving interventions that could make a difference" (see section 6.3 above)

- *“Finding the person:* approaches that enable the practitioner to explore and understand the individual’s life history, and its possible connections with current patterns of self-neglect. “Early experience, trauma, loss and relationship all figured strongly in the service users’ stories, and in the narratives of practitioners as they recounted how they had constructed bespoke interventions that responded to and took account of each person’s personal life experience, networks, relationships and motivations... Working with the fear, anxiety, embarrassment and shame that were sometimes present. Equally, people who use services emphasised their own resilience and determination, and valued practitioners who recognised and worked with those qualities” (see section 6.3 above)
- *Legal literacy:* “Mental capacity frequently featured in practitioners’ narratives, and was also recognised by managers as a key determinant of what intervention could and should take place. Knowledge of legal requirements was therefore an essential underpinning to practice.... The interface between different forms of legislation required skills in navigating and weighing different options, and expert advice in complex cases was vital”
- *Flexible and creative interventions* (to fit individual circumstances), negotiation (of what was within the service user’s zone of tolerance), “balance (between competing imperatives such as risk and safety) and proportionality (to moderate rather than seek to eradicate risk, in a way that preserved respect for autonomy).”
- *Coercive interventions* “were also sometimes necessary, and used, although the perspectives of people who use services showed that directive approaches were deeply unwelcome. Practitioners recognised that the cost was high in human terms, and proceeded only with reluctance, when a basic level of existence was threatened, or risks to others were extreme. But there were examples of such interventions that, with honest but empathic engagement, and as part of an ongoing relationship and care plan, produced positive change”
- *Multi-agency working:* “Convening practitioners who could contribute a range of disciplinary perspectives to self-neglect proved to be a powerful tool in practice”
- *“The importance of creating a strategic inter-agency infrastructure* to facilitate such practice cannot be over-estimated; referral pathways, discussion mechanisms, flexibility in work allocation practices, training and support all have a key role to play, as does an ethos of shared ownership between the agencies whose interventions can make a difference”.
- *Managing the personal experience of self-neglect practice:* taking responsibility for one’s professional support and emotional survival in the work is vital. Equally, managers also have responsibilities to ensure that supervision and support are prioritised, and that they facilitate rather than stifle the creative and brave practice that is often at the heart of the most effective interventions.

6.7.8. Achieving a balance between competing imperatives of independence, choice, wellbeing and safety is at the heart of effective practice in situations of self-neglect and refusal of services/ support. Available literature and guidance is replete with glib statements about dignity, respect, independence often with little practical support targeted on front line staff that helps them to knit these expectations in with a duty of care. PC has a new policy on managing non-

engagement of service users. It will support practice improvement in this respect. It refers to key aspects of decision making such as: mental capacity but also encouraging the person to accept the service; consideration alongside them of the potential risks, escalation of such circumstances (within the service and to ASC or health) if service refusal persists for more than 24 hours; and recording concerns. This area of practice requires whole partnership support so that all are working in a consistent and coordinated way.

- 6.7.9. The CQC management review record following the inspection of PC in June 2014 draws attention to a focus within PC in supervision and in policies on individual rights and choices but with very little on duty of care. This is not an issue solely for PC: it is at the heart of what went wrong and all agencies must focus on how to achieve a balance. This will be explored further in section 6.9 (below). Associated with this the CQC action plan also draws attention to:
- Concerns not raised and even when they were they were not acted upon
  - Little understanding of the MCA was demonstrated
  - No guidelines or understanding of appropriate action when a person self-neglects.
- 6.7.10. The current Medical Protection Society advice on dealing with non-compliant patients<sup>13</sup> was offered by the GP practice to this review as current guidance on this issue. There is no mention in it of contact with other professionals who may be in touch with the individual. More comprehensive guidance is needed. There is a need for a partnership-wide consistent approach to non-engagers.
- 6.7.11. Guidance for making effective judgements in balancing rights and risks has been drawn up following SCRs both in Surrey and in Slough, as part of broader guidance on working with risk. The following link gives access to partnership and council guidance on working with risk in Surrey as well as a recording tool. The guidance and tool in use in Slough is more recent.  
<http://new.surreycc.gov.uk/social-care-and-health/care-and-support-for-adults/protecting-adults-from-abuse/surrey-safeguarding-adults-board/safeguarding-resources-helpful-information-from-non-surrey-safeguarding-adults-board-sources/surrey-safeguarding-adults-multi-agency-procedures,-information-and-guidance>. The impact of a service users' choice must be carefully considered including attention to: level of risk; relevant legislation; person-centred practice; and potential contribution of a range of agencies (including front line provider services).
- 6.7.12. This guidance includes the following advice:
- **Choice must not be used as an excuse for inaction:** there is a responsibility to help the individual explore their decision and to understand the level of risk inherent in it. Regular opportunities must be offered to review that decision. A decision not to work with one agency may still allow contact with others who can maintain awareness of the situation and be proactive if the situation deteriorates. Issues of mental capacity must be considered and reference made to any other legislation relevant to the decision/ situation.

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<sup>13</sup> <http://www.medicalprotection.org/docs/default-source/pdfs/factsheet-pdfs/england-factsheet-pdfs/dealing-with-non-compliant-patients.pdf?sfvrsn=7>



- **Where an individual has mental capacity to make decisions, chooses to live with a level of risk** and declines support/ services, they will often have a right to do so. They must however be supported to understand the implications of their decision and they must formally consent to and take responsibility for the consequences of their decisions. This needs to be recorded.

6.7.13. Even when an individual is indicating that they wish to accept a high level of risk, this should not prevent the assessor from involving other agencies to share information about the risk and agree any available actions that will reduce or monitor the risk.

## 6.8. Mental Capacity Act and legal literacy

6.8.1. The principle of presumption of capacity was followed largely without question with ZZ. Her decision making was clearly problematic and her refusal of support resulted in severe risk and ultimately death. Her decision making should have met with firm but respectful challenge and absolute clarity with her about what the risks were for her of taking this approach.

6.8.2. The above discourse on self-neglect highlights (section 6.7) the significant role of considerations of mental capacity in balancing rights and risks. Central within this is that individuals must be supported to understand the implications of their decisions. Whilst agencies involved with ZZ are right that assessment of capacity was not until the end of the chronology indicated as necessary, the principles of the MCA and especially principle two<sup>14</sup> were of central importance. These are set out in the MCA (2005) Code of Practice<sup>15</sup>. All those involved with ZZ have a duty to comply with this. Such support was not recorded as forthcoming from any of those involved.

6.8.3. Practice with ZZ and feedback from organisations involved as part of this review reflect a need for better understanding of the MCA and its practice implications and of case law, and a greater use of the MCA and other relevant legislation to protect the welfare of individuals.

6.8.4. Examples from IMRs contributed to this review acknowledge and/ or reflect the need for development in this area of policy and practice. (Qualifying/ explanatory comments from the author are set out in brackets and *[in italics]*).

Organisation	Statement in IMR or supporting documents for the review
Care agency, PC	“ZZ had capacity and chose to live her life in her own way – which was her right. However, there came a point where this constituted a risk to her health and this needed to be flagged up by care workers and others involved in supporting her” and “Training has tended to focus on service user rights to be regarded as having capacity; it needs to include more about situations where that capacity can lead to self-harm” requires “recognition that there is a point at which

<sup>14</sup> Principle 2 of the MCA, 2005: “the right for individuals to be supported to make their own decisions - people must be given all appropriate help before anyone concludes that they cannot make their own decisions”.

<sup>15</sup> Department of Constitutional Affairs, (2007). “Mental Capacity Act 2005: Code of Practice”. London: TSO. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/224660/Mental\\_Capacity\\_Act\\_code\\_of\\_practice.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/224660/Mental_Capacity_Act_code_of_practice.pdf)

	capacity to make decisions is having a detrimental impact on a person's health and that this point is flagged up with appropriate professionals who can investigate further" and "There has been great stress placed on service user choice, service users achieving their outcomes, service users being independent and service users exercising control over their services".
<b>University College London Hospital</b>	"The understanding of capacity and duty of care to intervene using appropriate legal tools of the Mental Capacity Act or the Mental Health Act for partners in the community is lacking".
<b>ASC</b>	In respect of the ASC response to issues raised by the panel in the context of the MCA: "ZZ was clearly identified in ASC records as having mental capacity and engaging in discussions about her own care, therefore this is not applicable up to the time of this review" <i>[the MCA was however relevant as in paragraph 6.8.2 above]</i> . "The question of whether she was making 'good' decisions is about the quality of assessment, support planning and outcomes, rather than a question of mental capacity" <i>[it is also reliant upon working within the principles of the MCA]</i> .
<b>CQC</b>	In its regulatory plan following the inspection of June 2014 CQC draws attention to: a "focus in policies and supervision notes on independence, rights and choices, with very little on duty of care. Little understanding demonstrated of mental capacity and no guidelines or understanding demonstrated of appropriate actions to take when a person is self-harming (through self-neglect in this case)".
<b>GP Practice</b>	"The management of any adult patient with capacity for any condition is a consensual process. It requires their cooperation and consent. Until her final illness, at all material times ZZ had demonstrated that she had capacity. There was no reason to question her capacity. She had acted reasonably and rationally according to information available at the practice". <i>[There was a need however to inform and support her capacitated decision making]</i> .
<b>London Ambulance Service</b>	The LAS undertook an assessment of capacity on 9 <sup>th</sup> June 2014 when ZZ refused to be taken to hospital. They had received a call from carer 1.  The LAS Policy for Consent to Examination/ Treatment has been submitted to this review. The Operational Procedure OP14 (Managing the Conveyance of Patients Policy and Procedure) has not been forthcoming but it is presumed it carries the same principles.  The LAS tool for documentation of capacity assessment reminds staff of their duty of care. It asks them to document their course of action "based on the patient's level of capacity, the seriousness of the clinical condition and the risk of subsequent harm". <i>[It is not very clear about the factors to take into account when a balance needs to be struck where a patient has capacity but there is a high risk of harm]</i>

	<p><i>associated with their decision, except to seek advice].</i></p> <p><i>[At a panel meeting for this review ...LAS asked “where is the line to say she lacks capacity?” There may be a gap in clear guidance on this in LAS and if so this needs to be addressed].</i></p> <p>The guidance/ form reminds staff who have continuing concerns to seek additional advice from an LAS officer, clinical advisor or GP. <i>[This the crew on 9<sup>th</sup> June 2014 did: they called for the support of the GP].</i></p> <p>The LAS Policy for Consent to Examination/ Treatment states: “Patients need sufficient information before they can decide whether to give their consent: for example information about the benefits and risks of the proposed treatment, and alternative treatments. If the patient is not offered as much information as they reasonably need to make their decision, and in a form they can understand, their consent may not be valid.” <i>[The assessment form completed in respect of ZZ did not record that the risks and benefits of proposed actions were explained or consequences of not receiving treatment].</i></p> <p><i>[On the completed capacity tool in respect of ZZ there is no detail given to back up yes/ no answers (as the form requests). The main issue is whether she understood and was helped to understand the serious consequences (she was according to the GP, “moribund” 2 hours later)].</i></p> <p><i>[Practice in the context of supported decision making is a key issue for LAS and other agencies. The guidance and assessment form could offer more support on this. This needs to be underpinned with training].</i></p>
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- 6.8.5. Key themes in the context of mental capacity issues apparent in the case of ZZ and reflected here are in respect of: the need for robust supported decision making; the need to balance choice and independence with safety considerations, including robust supported decision making (explored in paragraph 6.7.12 above); analysis of risk alongside the service user as part of the latter; robust recording of decisions and assessments.
- 6.8.6. The term ‘duty of care’ is complex. It is frequently referred to by practitioners and often not understood except in the simplest of terms (i.e. that by virtue of the fact that they are in the position of formal carer the relationship with the service user means they (the carer and the organisation) owe a duty of care). This in itself takes practitioners no further forward except often to underline the conflict that they face between this duty of care and acting to uphold service user rights and choice. Leaving the concept there can simply serve to underline a dilemma and lead to feelings of impotence and resigned acceptance. For the term to become more meaningful to those who owe such a duty it is probably most helpful in practical terms to offer support in understanding the positive steps that they would need to take to avoid any claim of negligence or breach of duty of care. In simple terms for negligence to be established harm must have

occurred, the harm must have been reasonably foreseeable and a failure to act must be seen to have directly resulted in harm. This implies that carers and the organisations that employ them must as part of fulfilling a duty of care identify or facilitate identification of any potential risk of harm (risk assessment) and put in place any measures indicated by the assessment to mitigate the likelihood of harm.

- 6.8.7. In looking at what professionals could do or could have done to avert harm, consideration of legal alternatives for proactive and proportionate intervention is necessary. Legal literacy is therefore important amongst those who are making decisions in cases such as that of ZZ. Staff need to be aware of the complex legal framework and keep their knowledge up to date. Where there is doubt about legal issues, expert legal advice must always be sought by staff within organisations. The Camden high risk/ complex cases policy, procedure and guidance does include a table of legal options. This is limited in scope and could go further and be set out so as to give practical applications of such legal alternatives (including examples from the case of ZZ). Tables that might offer support with this as examples are set out in serious case reviews elsewhere for example 'Ann' Sheffield<sup>16</sup> and 'Mr BB' Westminster. This has training implications across agencies as well as implications for ensuring the availability of legal advice to those who require it. The recent research into self neglect<sup>3</sup> identifies an issue in respect of the latter: "Not all local authorities... allowed ...unrestricted access to legal advice, with an internal market operating, with attendant cost implications. The result was that adult social care managers were expected to screen the level of need before social workers could ring the solicitor for advice and guidance". Camden needs to ensure that such restrictions do not impede timely decisions about legal options to address risk.
- 6.8.8. Mental health issues/ bereavement and the potential impact on decision making are explored by ASC and PC as part of this review. ASC state: "with regard to mental capacity, it is quite possible that the death of ZZ's husband might have contributed to a lack of motivation to mobilise off the sofa or to eat enough to maintain adequate nutrition in the weeks or months prior to her death". ASC state that: "If ZZ's condition deteriorated to a point prior to her hospitalisation that she was unable to engage with the home care workers, or which indicated any marked deterioration of mental capacity or communication, ASC would expect that the home care workers would raise their concern with the agency and that it would be communicated to ASC by the agency". This did not happen.

## 6.9. Staff support/ supervision

- 6.9.1. Staff supervision should take place on a regular basis. The chronology indicates that it did with the key front line carers supporting ZZ (see section 5 above). Supervision took place in the office and in ZZ's home. The PC supervision policy is brief (one page) and covers how and when (frequency) supervision will take place and that it must be recorded. It states that supervision will address areas including: providing direction; giving advice; performance and standards of work; offering support; discussion of best practice; staff member concerns; health and safety. On a superficial level in the case of carers supporting ZZ it did fulfil these criteria but critically it failed to

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<sup>16</sup> <https://www.sheffield.gov.uk/caresupport/adult/adult-abuse/professionals/serious-case-reviews.html>

establish that there were in fact concerns and issues relating to the care of ZZ. The records appear to indicate that an absence of concerns expressed meant no concerns existed. Supervision needs to be more incisive and perhaps with a number of standard questions that might get to the bottom of any issues. Following the death of ZZ PC might opt for standard questions within supervision of staff around service refusal; safeguarding and neglect; and pressure ulcers. In addition, in much the same way that a set of questions such as those set out in the DH guidance on risk (supported decision tool)<sup>7</sup> might encourage service users to express their concerns and wishes, so too might a similar approach in supervision especially with staff members who may lack confidence in expressing concerns. The CQC inspection of June 2014 highlighted that in general staff supervision was sporadic and that issues were not discussed when they should have been. Daily logs were in general not read by managers. This too is a means of supervising practice and it was not happening.

- 6.9.2. The staff handbook is clear that care work can be stressful and that staff should use office coordinators/ team leader for support or back-up. However, staff need to know that when they ask for support this is going to be helpful and constructive. They need to be confident in taking concerns to managers. It is not clear that this is the case. For example, we are aware from ZZ's neighbour that on one occasion a carer sought advice from the neighbour's wife who suggested that the carer discuss the issues with her manager. There is no record of a conversation with a manager at this time. When carer 1 reported serious concerns to the team leader on 5<sup>th</sup> June 2014 the team leader asked her for a written report before she would share this with ASC. This was neither a proportionate response nor likely to have been experienced as supportive by a carer who, we know from CQC, worked a 64 hour week just prior to the death of ZZ. The report went to ASC on the day ZZ went into University College London Hospital (9<sup>th</sup> June 2014).
- 6.9.3. Likewise in ASC, supervision and oversight fell short of expected standards. From December 2011 ASC was implementing a new matrix management system to social work. The panel was told that "as a result there was limited supervisory oversight or sense-checking of the content of assessments and reviews". This it says may have contributed to the poor quality of these processes despite compliance with statutory requirements. Again on the surface requirements and timescales are complied with but the depth and quality of supervision was clearly inadequate. This is reflected in the quality of assessments and decision-making highlighted in this report. Social work practice was inadequate on a number of levels. Supervision failed to identify or address this.
- 6.9.4. Robust managerial support and supervision is essential in working with risk. Supervision policies must facilitate discussion of cases involving significant risk. Managers must support individual staff in specific cases and ensure necessary development opportunities are made available. The research on self neglect<sup>3</sup> highlights that "feeling helpless yet responsible is a very uncomfortable place to be. Such experiences indicated the need for robust supervision and support mechanisms to be in place". This reflects the experience of working with dilemmas such as that described in paragraph 6.8.6 (above) around holding the balance between duty of care and service user choice. With issues such as this

staff sometimes struggle even to articulate the dilemma. This is why frameworks such as that set out in the supported decision tool (DH: 2007)<sup>7</sup> might be as helpful in supervision as they are with service users because they demystify the complex language often used and help staff to get to the heart of the matter. This is why prompts to discuss regularly occurring themes can help too.

- 6.9.5. Opportunity for reflection on practice in complex cases is essential. Group supervision or group opportunities for reflective practice need to be available for staff.
- 6.9.6. The research flags up the emotional and personal experience of self-neglect cases and the need for support in this. University College London Hospital recognised this in offering counselling and debriefing for staff who had been involved in caring for ZZ on 9<sup>th</sup> and 10<sup>th</sup> June 2014.
- 6.9.7. It is important to take on board a key message in respect of staff support/ supervision from *Making Safeguarding Personal* (a national programme which has been funded by DH and within which Camden is participating). The programme has underlined that in order to achieve the shift in practice required, if personalised approaches and outcomes are to be a reality, staff supervision needs to be a priority. Staff supervision is a means of developing staff to work in this way and a means of monitoring the extent to which this is embedded in practice. Opportunities for group supervision and case discussion are vital.

## 7. CONCLUSIONS

- 7.1. At an earlier stage, life for ZZ included time spent in the company of her sisters and an active working life in which at one stage she and two of her sisters worked together. She married and separated and then spent most of the last 40 years of her life with two long term partners. Her sisters, brother-in-law and nephew all kept in close weekly contact and her nephew, in particular, gave practical support and visited at least twice weekly once her partner became ill. We know that ZZ did not want to be alone: she even asked her nephew and brother in law if one of them would move in with her following the hospitalisation of her second long term partner in 2011. ZZ was lonely and isolated following the death of her partner in May 2013 (and when he was in hospital). This was compounded by her long term condition: agoraphobia. Carers who came in three times each day, as well as ZZ's nephew, provided the company that we know ZZ wanted, but she was increasingly reluctant to accept support with identified care needs from them.
- 7.2. ZZ's reluctance to accept care, support and treatment had been a characteristic over a significant period of time. There is evidence of specific examples of this between 2011 and June 2014 and before this for example in relation to housing issues and psychiatric support. This reluctance to engage with support and treatment at some point in her final years tipped into self-neglect. The point at which this became a significant risk, because ZZ was neglecting personal care needs and existing on an increasingly inadequate/ insufficient diet, was never identified by front line carers who spent around two and a quarter hours with her every day from December 2011. It was not identified by professionals either.

- 7.3. There was little evidence of any connection with ZZ “the person” on the part of carers or professionals. This would firstly have supported insight into and understanding of some of the potential reasons for her turning away support, such as anxiety and depression (in respect of which there are clear long term indications). This lack of insight into those causal factors mitigated against any possibility of preventive action through addressing those causes. The lack of connection with her was also significant in that conversation with ZZ and establishing a relationship where something was known about her as a person may have provided the necessary “way in” to beginning to talk to her about her problematic and risky behaviour. That she was obstructive to efforts to help her is clear, however there is no record of efforts to establish a relationship that would allow staff and professionals to move beyond that obstruction.
- 7.4. Regular checks and processes within agencies that would, through routine surveillance of key issues, enable professionals to pick up that all was not well with ZZ were not in place. Her refusal of support and the fact that she hid the extent of the problem (at least later on in the chronology) indicate that this would have been important. Routine attention to the signs and symptoms that indicate a risk of skin breakdown or of risk in relation to nutrition and triggers for carers to escalate concerns in these respects (and to seek specialist advice) were absent. The GP practice did not identify that ZZ had not ordered repeat prescriptions. Therefore a medication review was not triggered. The GP practice failed to pick up on a pattern of refusal of regular reviews and, in the context of the chronic conditions of which they were aware, to be proactive *alongside other agencies* in seeking to engage with ZZ. Such routine checks and processes by the GP and the care provider might have triggered more proactive attempts at engagement.
- 7.5. The symptoms of the neglect were not identified and yet the condition in which ZZ presented at University College London Hospital on 9<sup>th</sup> June 2014 indicated that the neglect had been going on for some considerable time. Carers who visited her several times every day failed to notice the steady and serious decline or the acute signs of neglect towards the end. ZZ weighed just 30kg (around 4 stone 10lbs) on admission to hospital. She was covered in faeces and the extent and seriousness of pressure ulcers was extreme. Basic practice in assessment, care planning and review fell very short of expected standards with a lack of focus on specific areas that should have been identified and followed through in assessments and reviews. This would have allowed formal identification of needs and risks and would have evidenced that these were not being adequately addressed through the care plan and the reasons for this. Critically when information was recorded about lack of weight bearing, mobility, nutrition and skin issues this did not trigger a referral to a specialist such as occupational therapy, dietician or tissue viability nurse. Neither was there communication between the provider and the commissioner about the extent to which the care plan was effective. Supervision by managers should have provided scrutiny and challenge as well as support. It did not.
- 7.6. Risks were rarely formally acknowledged and recorded and therefore plans to manage and keep track of them were lacking. Even where serious risks of malnutrition, falls and self-neglect were recorded on ASC reviews/ assessments these were not addressed or considered in any detail. Nor were they shared across relevant professionals. There was a failure to collate information about risk into a holistic assessment in order to inform shared decisions and actions across the range of professionals and staff. Professionals were not proactive in informing

ZZ of the range of risks in order to support informed choices and to ensure that she fully understood the consequences of her lack of engagement with/ acceptance of support. People who use services need to inform and be informed by the risk assessment. This area of work requires a focus on developing support and guidance available locally, in the light of lessons from this report and the available guidance highlighted in it.

- 7.7. The risk of pressure ulcers in ZZ's situation was clear. A range of risk factors was present. In common with other areas of risk in ZZ's life the risk was not identified and the specialist input required was not sought. The risk was therefore not managed. This was a serious oversight with devastating consequences. Available guidance needs to be integrated urgently into practice.
- 7.8. ZZ was persistent in declining personal care and carers and professionals were consistent in the response that ZZ had capacity and therefore she was within her rights to do so. The duty of care owed by carers and professionals means that they must go beyond this response to an identification of the potential consequences of such decision making *alongside the service user* and an appraisal of the likely risks (potential harms) and possible ways of mitigating these. This was not evidenced in records. Responses may at times require coercive actions where the risk is substantial. This requires practitioners to understand and consider the legal framework within which they operate and to apply it where necessary.
- 7.9. In this context improvement in applying the requirements of the MCA in practice are indicated as necessary by this review. In particular, the implications of principle two of the Act are significant. "The right for individuals to be supported to make their own decisions – people must be given all appropriate help before anyone concludes that they cannot make their own decisions." Practitioners must ensure that individuals have and understand all of the information required on which to make a decision and that this is recorded. This means at times confronting individuals such as ZZ with difficult information about the consequences of their decisions including details about issues such as pressure ulcers and including that decisions could lead to loss of life. This is learning for ASC; the provider service; the GP and the ambulance service.
- 7.10. Self-neglect is a prominent issue in this review, bringing together all of the issues mentioned above into complex circumstances that require skilled practice from a range of professionals and staff. The learning from this review needs to be harnessed to offer advice and support to staff in identifying and working with this issue. Key deficits in the approach to this case (in the light of both the learning from the case of ZZ and underlined in recent research findings) are around:
  - the lack of attempts to engage with ZZ;
  - the failure to engage relevant specialists to address the risks presented for ZZ;
  - the lack of respectful challenge and persistence in supporting ZZ's understanding of the risks;
  - the care management model that closed this case except for annual review when what was required was persistence and continuity;
  - the inadequate support and supervision of staff working in and managing such challenging situations;



- legal literacy and especially understanding the requirements of the MCA and the balance between choice and safety.

7.11. Regulation and procurement have a crucial role in facilitating, supporting and testing out practice in all of these areas. This role is underlined within this review.

## **8. RECOMMENDATIONS**

### **8.1. Self-neglect**

- 8.1.1. In the context of implementing expectations in respect of self-neglect, set out in the Care Act 2014, Camden SAPB should create a task and finish group for working with self-neglect with the aim of raising awareness and improving and supporting practice. It will support/ promote:
- The development of guidance for the whole partnership on approaches to identifying and working with self-neglect and key underlying principles. This will draw on the key learning points from this review and include practical guidance to raise awareness of and offer support to front line carers.
  - Ensure that key aspects of the MCA are reflected in the guidance.
  - Development of learning and development opportunities including coordinating multi-agency training and adopting other means of disseminating good practice.
  - Engagement of commissioning and procurement in disseminating lessons and monitoring impact on practice; equipping commissioning and procurement as an effective partner in the appropriate sharing of intelligence and concerns.
  - Clear referral pathways for common scenarios.
  - Further development and promotion of the HRP in light of the learning from the case of ZZ.
  - Focus on self-neglect in case file audit exploring how far self-neglect is identified and what the outcomes are for people.
  - Collecting and analysing data on self-neglect as part of SAPB information (again a focus on number of cases and outcomes of those cases).

### **8.2. Proactive engagement with people who are reluctant to engage with services/ support/ treatment**

- 8.2.1. Camden SAPB will establish key principles in working with individuals who are reluctant to engage and promote this as a basis to strengthen existing guidance across organisations. The aim will be to integrate the learning from the case of ZZ into all guidance in all organisations. Weaknesses in existing guidance in light of the lessons learned must be addressed in the organisations involved in this review.
- 8.2.2. Camden SAPB will seek assurance that key aspects of the MCA are reflected and in particular the principle of supported decision making.
- 8.2.3. Key lessons on this issue will be disseminated to care providers through procurement and relevant forums.

8.2.4. Prevention through identifying at risk groups who are failing to engage with services/ treatment, and being proactive in encouraging engagement, features in the GP practice action plan from this review. This will be monitored by the Camden SAPB. Camden SAPB will disseminate the learning across Camden GPs and to NHSE.

### **8.3. Engaging with people who use services and their families/ carers**

8.3.1. Camden SAPB will continue to develop its engagement as a whole partnership in *Making Safeguarding Personal* ensuring that person-centred principles are embedded in all relevant policies, procedures and guidance, in front line practice and in commissioning of services.

8.3.2. It will identify several basic and practical tools (such as the supported decision tool (DH: 2007) to support front line staff across agencies to begin to make this shift in practice (from completing processes and ticking boxes to having meaningful conversations with people about the relevant issues and outcomes for them).

8.3.3. There will be a focus on this aspect of practice in case file audits.

8.3.4. The SAPB will evidence training and other support in place to develop the necessary skills so that staff can make this shift in practice: specific training courses; reflective learning opportunities; and staff supervision.

8.3.5. The SAPB will seek evidence of engagement with carers and informal networks.

### **8.4. Mental Capacity Act and duty of care**

8.4.1. In the context of working with people who self-neglect and/ or refuse services, a practical application of the fundamental principles of the MCA is central.

8.4.2. Alongside a continuing emphasis on engagement in training across all organisations there will be:

- A focus in case file audit on practice in respect of the core principles of the Act and in particular principle two (supported decision making) and the balance of principle one (presumption of capacity) with duty of care.
- All organisations must put in place support for all levels of staff to help them to understand how the principles of the MCA must be worked out in practice. Real examples must be used to convey this learning and to support staff/ professionals in understanding their responsibilities under the MCA Code of Practice. Camden SAPB will hold organisations to account in this respect.
- The case of ZZ will be used in MCA training to demonstrate the importance of balancing the presumption of capacity and duty of care and the significance of principle two of the MCA.
- Camden SAPB will promote the benefits of integrating the spirit of the MCA into practice through the sharing of real case studies.
- Camden SAPB will ask of commissioners that they have assurance of integration of the requirements of the MCA in practice.

- Camden SAPB will respond to the recommendations of the House of Lords Scrutiny Committee on the MCA.

## 8.5. Working with risk

- 8.5.1. ASC will lead improvement in this area of practice with the re-development of its existing policy and guidance on working with risk as well as the High Risk Panel. This will incorporate learning from this review as well as reference to practice development elsewhere from similar case reviews.
- 8.5.2. Guidance outlining joint principles in working with identification, assessment and management of risk will be developed and agreed across all partner agencies to Camden SAPB.
- 8.5.3. ASC will coordinate the development of tool(s) for recording risk assessment and risk management in line with the new guidance.
- 8.5.4. Camden SAPB will develop an implementation plan to include staff training and the support and development of front line staff in working with risk.
- 8.5.5. Specifically training in risk assessment and risk management will be reviewed in the light of this SCR across agencies.

## 8.6. Pressure ulcers and nutrition

- 8.6.1. Camden SAPB will facilitate through ASC commissioning and procurement and with the support of relevant health professionals:
- 8.6.2. **Awareness raising primarily across domiciliary care agencies in respect of the risk of pressure ulcers.** To include:
  - The need to identify early signs and symptoms
  - How/ when to escalate concerns
  - Who needs to be involved where there is a risk identified
 This to be supported by commissioning and to form a key focus in contract monitoring. Awareness of links between malnutrition and pressure ulcers to be promoted in addition.
- 8.6.3. The partnership will operate a principle of proactive interaction with those who are in high risk groups or who are known to be at risk and engage relevant partners in achieving this.

## 8.7. Engagement of the Director of Public Health on Camden SAPB

- 8.7.1. There are two key areas in this review that indicate the role of the Director of Public Health.
- 8.7.2. The Director of Public Health to be requested to engage with Camden SAPB in supporting the raising of public awareness in respect of pressure ulcers.

## 8.8. Improving practice in respect of assessment, care planning and review

- 8.8.1. This includes the need to communicate across agencies so that all agencies are sighted on key issues, keep track of developments, agree responsibilities and accountabilities and offer support to achieve positive outcomes.
- 8.8.2. Member agencies to Camden SAPB will specifically ensure that key assessments, reviews and any changes to agreed care plans are communicated across all relevant agencies so that all are clear about the key issues and risks and all understand their roles and responsibilities.
- 8.8.3. Camden SAPB will disseminate the guidance on good multi-disciplinary assessment and on carrying out reviews set out in this SCR. This will include drawing attention specifically to the need to bring in specialist assessments/ expertise where indicated (for example tissue viability nurse; occupational therapy; and mental health therapy).
- 8.8.4. The extent to which practice reflects this guidance will be:
  - supported through training and staff support/ supervision, and
  - monitored through a focus on these aspects of practice and recording in future case file audits.
- 8.8.5. ASC will review recording formats for assessment, care planning and review to reflect the lessons from this SCR.
- 8.8.6. Locally commissioning and procurement will support providers in reviewing this area of practice and recording and focus on the regulatory requirement set out in paragraph 6.5.21 (above) of the SCR in respect of coordination and communication between commissioners and providers on care plans and reviews.

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**REPORT ENDS**