Safeguarding Adults Review

‘Brandon’

Commissioned by Camden Safeguarding Adult Board

Dated April 2025

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1. Introduction

1.1. In April 2023 Camden Safeguarding Adults Board ['CSAB'] commissioned a safeguarding adults review into the death of 'Brandon', a 54-year-old white British male who died in July 2022.

1.2. In 1997 Brandon fell from a prison bunk bed during a severe epileptic seizure and, after guards delayed taking him to hospital, he sustained a life-changing brain injury, resulting in paraplegia and he was unable to communicate verbally or non-verbally. Although he was initially placed in specialist residential care, in 2006, he moved to live with his aunt (who was 92 at the time of his death) after she asked to care for him in the community. She remained his informal carer at the time of his death, with support from another family member (the personal carer) who was employed through his financial deputy after a care assessment in 2012 and informally from other family members. District nurses, tissue viability nurses and other health professionals attended the home when required to support Brandon's complex health needs, but he did not have an ongoing package of care. No concerns were raised about conditions in the home or the family's physical care for Brandon.

1.3. In June 2022 private health professionals funded through his finance deputy raised concern that Brandon had become significantly malnourished and dehydrated and developed pressure ulcers, so a safeguarding referral was made in July 2022. A care agency started providing care the same day after Brandon's aunt was admitted to hospital. Brandon passed away three days later and although it was initially believed that this was due to asphyxiation on food, the postmortem determined that he died from advanced pneumonia, complicated by his neurological condition and/or heart disease.

1.4. CSAB agreed the case met the s44 criteria for a review as Brandon was in need of care and support, may have experienced neglect and there is reasonable cause for concern about how persons with relevant functions worked together to safeguard Brandon.

1.5. Brandon's family met with the author of this report, and their love for him shone through in everything they said and their actions throughout his lifetime. They saw his personality, his preferences and he was a highly valued member of the family. His aunt in particular was absolutely devoted to him, providing compassionate, diligent care for many years, for no compensation. One of the professionals who attended the learning events commented that given the complexity of Brandon's needs, the care the family had provided must have been truly outstanding, as he felt that most specialist care homes would have struggled to meet Brandon's needs over that period, with a rota of round-the-clock trained carers. Likewise, the GP commented that Brandon would not have lived as long as he did without "*exemplary*" care from his family.

1.6. The family were absolutely devastated by Brandon's death and the fact that this happened when they were not with him, and it is extremely unfortunate that the misunderstanding about the cause of his death has added to their grief. Because Brandon had been struggling to breathe and paramedics subsequently found a piece of food in his oesophagus, the family believed that he had choked, and that delays in providing quality CPR contributed to his death. However, the report author met with the medical examiner from the coroner's office, who explained that the oesophagus leads to the stomach (as opposed to the larynx and trachea which form the windpipe), so the item of food was not blocking Brandon's airway. This is evident from the fact that when the second ambulance crew had carried out basic CPR prior to removing the item of food, this caused his chest to rise, indicating there was no obstruction to his airway. When the medical examiner carried out the postmortem examination, he found no physical evidence of choking. Common signs of asphyxiation, such as trauma to the upper airways, burst blood vessels in the eyes and, in particular, around the heart, were not present.

1.7. Rather, Brandon had very severe pneumonia, which had advanced so much that empyema had developed. Empyema is the medical term for pockets of pus that have collected in the space between the outside of the lungs and the inside of the chest cavity, and this will develop if an infection such a pneumonia has gone untreated for a lengthy period.[1] It is likely that due to Brandon's brain injury, he did not display the usual symptoms of pneumonia, meaning that medical professionals who were trying to identify the cause of the decline in his physical condition were exploring other diagnoses, and this is explored further in this report. The medical examiner also discovered that Brandon had suffered a recent stroke, which had also not been identified by health professionals or the family due to his pre-existing symptoms arising from his brain injury, and this may have contributed to his poor condition. The medical examiner advised that given that the cause of death was advanced pneumonia, together with Brandon's other health needs, it is very unlikely that CPR could have been effective in the community even if carried out promptly, and that even if he was in hospital where antibiotics could be immediately administered together with resuscitation efforts, this may not have prevented his death. This view is reinforced by the view of a consultant gastrologic specialist from UCL who saw Brandon just 4 days before his death, who advised that he was not fit enough to undergo a colonoscopy and that even if abnormalities were found, he would not be able to tolerate treatment of this. His body was sadly too frail and weakened to survive his illness.

1.8. The author and members of the SAR panel and Safeguarding Adults Board wish to extend our sincere condolences to the family for their loss, and express our gratitude for their generous contribution to the review. We acknowledge that due to specific issues identified during the review process, publication of this report was substantially delayed to enable Metropolitan Police investigations to take place, and this delay has caused further distress to the family. We sincerely apologise for this. We hope that the fact it has now been possible to clarify the circumstances of Brandon's death, and identify lessons which will help to strengthen safeguarding for people with similar needs, will provide some solace to his loving family.

2. Description of Brandon

2.1. Brandon's family described that he had been a normal, independent and caring young man, with a quick wit and a cheeky face. However, from the age of 14 he became addicted to drugs and was involved in criminal activity to fund this, resulting in a short prison sentence for shoplifting. In 1997 Brandon fell from a prison bunk bed during a seizure, but guards negligently delayed taking him to hospital and he sustained a life-changing brain injury, resulting in paraplegia and he was unable to communicate verbally or non-verbally. The High Court awarded Brandon substantial compensation for these injuries, and directed that this should be overseen by the Office of the Public Guardian.

2.2. Brandon was placed in residential care and then a care centre, in 2006, he moved to live with his aunt (who was 92 at the time of his death) initially for respite then permanently, after she asked to care for him in the community. She was concerned that he was experiencing neglect in his care centre, describing him being left sitting in urine. She surrendered her own council accommodation and moved into a 3-bed flat in Brandon's name that was adapted to his needs by the Occupational Therapy (OT) service. A family member was employed as a personal carer, paid through the finance deputy and his aunt remained an unpaid, informal carer until his death. In 2012, a second family member took over the role of personal carer. At times, the professional financial deputy appointed by the court to manage Brandon's compensation fund tried to make arrangements for specialist health care or additional care in the home to support Brandon's aunt, but the family felt that they could meet his needs without intervention and were suspicious that the deputies were motivated by money.

[1] Empyema - NHS

2.3. Brandon's aunt had photos of him at all ages across her walls and described him as alert, calm and "*not hard to look after*", and his sister showed photos of Brandon gently holding infant relatives. Initially Brandon could walk with support and had normal bowel movements, but his condition deteriorated after he had a bad reaction to being given vaccinations for the flu and pneumonia on the same day. He then required enemas and was not able to walk, but he could stand to move from his bed or chair to a wheelchair. His aunt would take him out in his electric wheelchair and they were a familiar sight in the local community. Practitioners described Brandon as being responsive, as he would orient towards voices, acknowledge them and smile, and could indicate through his behaviour whether he liked or disliked something. He clearly held affection for his aunt and would look for her if she was out of the room.

2.4. Due to Brandon's limited mobility and posture, he had difficulties at times with pressure ulcers. After developing serious pressure ulcers in 2015, Brandon was assessed as being eligible for Continuing Healthcare by the North Central London CCG, which meant that they were responsible for fully funding his publicly funded health and social care support. His personal carer was then funded by the CCG's Continuing Healthcare team through a personal health budget, which was paid via his financial deputy. He received support from district nursing, tissue viability nurses and occupational therapy when required. Due to muscle spasticity, Brandon started receiving Botox injections in his neck in January 2020, and as a result, he had limited cough reflex and took fluids through a straw although he continued to be fed soft foods normally.

2.5. As he continued to gradually lose weight over time, Brandon became quite bony, but nurses told his family that this was because he could not use his muscles. The family had ongoing discussions with the GP about Brandon's weight, resulting in a referral to Royal Free Hospital for screening for bowel cancer in May 2022, but he was too frail for a colonoscopy to be safely carried out. However, when a new case manager was appointed by Brandon's financial deputy in June 2022, she was extremely concerned about his poor condition and while referrals were made to explore various health diagnoses, in the absence of a clear reason for this, she raised safeguarding alerts that his health and care needs may not be fully met by the family. She consulted with the professional network, and started to explore specialist residential placements for people with complex neurological conditions. The family were resistant to this, not only because they believed they were meeting his needs well, but because of the negligent care they felt he had received previously received (in 2006) in the same residential home the case manager was exploring. However, when Brandon's aunt had an accident and had to be hospitalised due to her own injuries, the family reluctantly accepted that the ICB's Continuing Healthcare team should arrange a private agency to provide carers in the home, as only the family member who was Brandon's personal carer had received the specialist training to meet his care needs, and he could not provide round-the-clock care single-handed.

2.6. It is incredibly sad that after her years of dedication, Brandon's aunt could not be with him when he died a few days after her hospital admission, and she was very distressed that he was without any family around him when he passed... "*He would have been looking for me, wondering why I wasn't there."* The family were strongly of the view that although he had lost muscle, he was "*definitely not dying*" at the point she was admitted to hospital, but in light of his advanced pneumonia, it is likely that he was not showing diagnosable signs of his illness as doctors struggled to identify the reasons for the decline in his condition. Equally, it is unfortunate that professionals had questioned whether this could be attributable to the family's care. While it is commendable that practitioners demonstrated professional curiosity about his poor health, in particular the extremely proactive response of the case manager and wholly appropriate to make safeguarding referrals in the absence of an alternative explanation to ensure Brandon's safety, this was very distressing for the family. Brandon's father died shortly after he passed, and the family felt that his heart was broken over Brandon's death.

3. Safeguarding Adult Review process

Purpose of a Safeguarding Adult Review

3.1. The Care and Support statutory guidance[2] sets out that the purpose of having a Safeguarding Adult Review (SAR) is not to re-investigate or to apportion blame, to undertake human resources duties or to establish how someone died. Rather, it is to establish whether there are lessons to be learned from the circumstances of the case about the way in which local professionals and agencies work together to safeguard adults, review the effectiveness of procedures (both multi agency and those of individual organisations) and inform and improve local interagency practice by acting on learning.

3.2. There is a strong focus on understanding the underlying issues that informed agency and professionals' actions and what, if anything, prevented them from being able to help and protect Brandon from harm. The learning produced through a SAR concerns 'systems findings'. Systems findings identify social and organisational factors that make it harder or make it easier for practitioners to proactively safeguard, within and between agencies.

Themes

3.3. The CSAB prioritised the following themes for illumination through the SAR:

- To consider the role of paid carers when they are also family members and informal carers and statutory Carers Assessments and consider how carer strain is identified
- Consider the issues that arose in relation to Brandon's feeding and effectiveness of information sharing
- To consider issues of training and competence in assessing people with a learning disability as a result of an acquired brain injury and complex physical and health needs
- To consider if any agencies could have done anything differently to identify the reasons for Brandon's declining health at an earlier stage
- To consider how the system and multi-agency arrangements for services for people with complex needs are commissioned and managed on a multi-agency basis and how to ensure safeguarding needs are identified in relation to:
    - Commissioning care and support for Brandon with CHC, managed under direct payments
    - The contract monitoring and review of CHC commissioned services
    - The role of the CHC assessment and panel
    - The reviews of Brandon's health and social care needs
    - Sharing information between agencies
- To provide multi agency safeguarding recommendations for learning and development to support people with complex needs under continuing health care (CHC) and the interface with the Office of the Public Guardian.

Methodology

3.4. The case has been analysed using a learning together approach, through the lens of evidence-based learning from research and the findings of other published SARs.[3] Learning from good practice and a discussion of the legal framework have also been included. By using that

[2] Care and support statutory guidance - GOV.UK

[3] Preston-Shoot, M., Braye, S., Preston, O., Allen, K. and Spreadbury, K. (2020) National SAR Analysis April 2017 – March 2019: Findings for Sector-Led Improvement. London: LGA/ADASS

evidence-base, the focus for this review has been on identifying the facilitators and barriers with respect to good practice. The review has adopted a whole system focus.[4]

3.5. The overarching purpose of the review has been to learn lessons about the way in which professionals worked in partnership to support and safeguard Brandon. This review was supported by a panel of senior representatives from agencies involved in the investigations. In addition, relevant partners completed a chronology of involvement from their case files, commenting on whether their local policies and best practice standards were applied. The author used these to draw together an Early Analysis Report, summarising the agency returns to provide a framework for multi-agency discussions at a learning event with front-line practitioners who worked directly with Brandon. Additional meetings also took place with a number of practitioners involved in Brandon's case who had either not been available to attend the learning events, or whose relevance to the review became clear as issues were explored. A separate meeting also took place with the senior managers who oversaw the services involved in supporting him and were responsible for oversight of policy implementation. To resolve the queries that arose during the course of the review, meetings took place with the medical examiner from Camden Coroner's Office and the Metropolitan Police. The agencies (through the panel and Safeguarding Adults Board) have also had an opportunity to comment on the report's findings and recommendations.

Contributing agencies

3.6. The following agencies provided documentation to support the SAR:

- North Central London ICB:
  - CHC Team
  - GP Surgery (Prince of Wales Group)
- Central and North West London NHS Trust (CNWL)
  - District Nursing
  - Tissue Viability Team
  - Speech and Language Therapy
  - Physiotherapy
  - Occupational Therapy
  - Community Neurology
- London Borough of Camden
  - Adult Social Care (including Direct Payment Team)
  - Adult Safeguarding
  - Occupational Therapy Team
- University College London Hospitals NHS Trust (UCL)
  - Neuro Focal Spasticity Clinic
  - Colorectal and General Surgery Clinic
- United Care UK
- Office of the Public Guardian
- Financial Deputy (Thomson Snell and Passmore LLP)
- London Ambulance Service
- Neuro Health Service
- Royal Free Hospital
- Metropolitan Police
- Camden Coroner's Office

[4] Braye, S., Orr, D. and Preston-Shoot, M. (2015) 'Learning lessons about self-neglect? An analysis of serious case reviews.' Journal of Adult Protection, 17 (1), 3-18.

3.7. It is of note that on 1 July 2022, Integrated Care Boards (ICBs) became legally established through the Health and Care Act 2022, and Clinical Commissioning Groups (CCGs) were closed down. North Central London CCG had therefore been responsible for Brandon's health care in the community but these functions were taken over by the North Central London ICB in the week prior to his death.

Involvement of Brandon's family

3.8. Brandon's sister and aunt met with the report author in August 2023 to share their memories of Brandon, and their concerns in relation to the actions of the agencies involved and circumstances of his death. Brandon's brother-in-law, who was his personal carer also met separately with the author. The family provided relevant documentation, and because this included Brandon's death certificate from the coroner and logs and reports from the London Ambulance Service, it was possible to discover that Brandon's death had not been caused by choking as the family and CSAB had believed, but was due to pneumonia. The family have been passionate about uncovering the truth about Brandon's death, and although this has not been what they expected, the author is extremely grateful for their assistance in providing the key evidence to ensure that this report accurately reflects the circumstances of his death. The family's commitment and love for Brandon have been very inspiring.

4. Narrative chronology

4.1. While serving a short sentence for shoplifting offences in 1997, Brandon fell from a prison bunk bed during a seizure and, after guards negligently delayed taking him to hospital, he sustained a life-changing brain injury resulting in paraplegia and he became unable to communicate verbally or non-verbally. The High Court awarded substantial damages to Brandon and the Office of Public Guardian was involved in respect of his financial affairs, so some care he received was privately funded. The court appointed a financial deputy to manage the day-to-day administration of his compensation.

4.2. After being placed in residential care and then a specialist care centre, in 2006, Brandon moved to live with his aunt, initially for respite, then permanently after she asked to care for him in the community due to her concerns that he was experiencing neglect in his care centre. She surrendered her own council accommodation and moved into a 3-bed flat in Brandon's name that was adapted to his needs by the occupational therapy (OT) service. A cousin was employed as a personal carer and his aunt remained an unpaid, informal carer until his death.

4.3. From November 2011 (until December 2012), a private brain injury case management company started working with Brandon, who referred Brandon to ASC for a care needs assessment after the aunt was injured in a fall in February 2012, as previous referrals had been blocked by the family. After a period of 24hour care from ASC, another family member became personal carer, in addition to a care agency initially providing twice daily visits to assist with transfers. District nurses, tissue viability nurses and other health professionals regularly attended the home to support Brandon's complex health needs. No further referrals were made to ASC in this period.

4.4. In August 2015, district nurses (who were visiting every other day) contacted ASC to request a review of Brandon's care and support needs as he had developed a grade 3 pressure ulcer on his back due to poor posture and there were concerns this was a safeguarding issue. When contacted by ASC, the aunt advised that although she was careful in respect of providing pressure ulcer care consistently for Brandon's sacrum and buttocks, she was unaware that a pressure ulcer could develop on his back and had thought it was a graze. An urgent OT referral was made to review seating, hoist and transfers and this assessment took place within 10 days, noting that his privately funded wheelchair was not sufficiently supportive. He was seen every 3 days by the district nurses (including larval treatment to remove necrotic tissue).

4.5. Brandon was assessed as eligible for Continuing Healthcare in December 2015 and his finance deputy was notified of this by Camden. His personal carer was then funded by the CCG's Continuing Healthcare team through a personal health budget, which was paid to his financial deputy. For administrative reasons, the payment was made by the London Borough of Camden then recharged to the CCG. District nurses, tissue viability nurses and other health professionals regularly attended the home to support Brandon's complex health needs, including annual frailty assessments, pressure ulcer treatment, blood test and OT support. No concerns were raised about conditions in the home of the family's physical care for Brandon, although aunt was at one point paying the personal carer from her own money, so a personal health budget (PHB) application was submitted. However, his finance deputy continued to struggle to engage with the family, including concern in 2018 that the personal carer would not carry out mandatory training, although this was subsequently resolved. The family also been resistant to a case manager due to the cost to Brandon's funds, and felt that they were able to meet his needs without additional intervention.

4.6. Due to muscle spasticity, Brandon started receiving Botox injections in his neck in January 2020, and as a result, he had no cough reflex and took fluids through a straw although he continued to be fed normally. Brandon was discussed in CNWL's Multidisciplinary Team (MDT) on 6 July 2020. It was raised that the aunt had his best interest at heart but wasn't using the pressure ulcer prevention equipment as required. Following an initial assessment, the district nursing team were optimistic that with their input, wounds would heal properly.

4.7. Brandon's aunt raised concerns with his GP in April 2021 that his weight had dropped, and by October it was noted that due to substantial muscle atrophy, his prominent shoulder blades were causing pressure sores although these had improved with treatment from district nursing. In June, Brandon was referred into Camden's Neuro and Stroke team, and occupational therapy and physiotherapy appointment started, to support with equipment, exercises and positioning. A referral was made to the Wheelchair Dietitian Service, but this was declined as they could not weigh him, and the carer was asked to arrange for him to be weighed at his next wheelchair appointment. SLT assessed that Brandon needed to be on a soft diet with thickened fluids, which the family confirmed they were following, and they were advised to be consistent in using his splints to prevent his muscles contracting. On 10 August 2021, the finance deputy wrote to Camden ASC requesting a reassessment due to Brandon's failing health. The deputy continued to contact the family, reiterating that CQC required a case manager to be appointed.

4.8. A full holistic assessment of Brandon's physical and mental health needs was completed by CCN on 16 August 2021. Brandon's aunt talked about getting older and her concern that she might not be able to look after the patient anymore and mentioned the potential for his sister to take over the role. Brandon's weight loss was discussed, but his aunt declined dietitian and said he'd been eating well with snacks between meals. CCN discussed advance care planning in Resus, agreed he should be for full escalation in the event of ill health. His aunt talked openly about Brandon's decline with less movement and lowered health. Brandon was seen by the TVN on 18 August 2021, when his pressure ulcers were noted to be healing. In September 2021, district nurses made a referral to the dietician and Brandon was seen by Speech and Language for a swallow assessment when advice was given around mashed food and thickened liquids.

4.9. On 4 October, the CCN raised concerns about Brandon's weight loss with the GP. He was visited by physiotherapy who gave advice around positioning, pressure care and orthotics. Brandon was discharged from the TVN later that month as his pressure ulcers had healed and district nursing reduced the frequency of Brandon's visits from every other day to every 3-5 days. He was also referred to UCL's spasticity clinic, and the physiotherapist conducted a telephone consultation in January 2022, when Brandon's aunt raised concern that Brandon "*was not opening his mouth like he used to when [she] is trying to feed him*", she felt he was still eating enough calories, but more slowly. She had not been using his splints and pads as she

found them too difficult to apply. The physiotherapist gave advice to Brandon's aunt about using hand splints and placing a small towel under Brandon's chin to allow air to circulate and a gentle stretch, and this was followed up in subsequent telephone consultations at two-monthly intervals while awaiting an in-person appointment at the spasticity clinic. Due to blood in his urine in February 2022, he was referred to UHL's urology department. Brandon's pressure areas were checked regularly and up to May 2022, these areas were intact, although there was some redness on his scapular and lumber spine, slightly blanching when touched.

4.10. In March 2022, Brandon's financial deputy wrote to his family, highlighting that because they were directly employing a personal carer for Brandon, CQC regulations required that someone who was CQC qualified had to oversee his support and training. As the deputy could not be CQC registered themselves, they were required to instruct a case manager as otherwise Brandon would lose his entitlement to direct payments for his personal carer. The family reluctantly agreed to this, and after approaching various case managers, Neuro Health was commissioned to support Brandon in June 2022.

4.11. In April 2022, Brandon had a cystoscopy at UCL's urology department for suspected urological cancer as blood had been observed in his urine, but no abnormalities were identified and he was prescribed antibiotics for a bladder infection. Due to this appointment, his appointment at the spasticity clinic was delayed. Brandon's aunt raised concern with the GP again on 4 May 2022 that he was 'all skin and bones' and that although he had no pressure sores, his skin was becoming red and sore in areas so a referral was made to OT, who were concerned that the family carers were not using Brandon's splints, so were given further advice on this, and a referral was made to the spasticity clinic. The spasticity clinic's physiotherapist had a further telephone consultation with Brandon's aunt on 18 May 2022, when she discussed being unable to fit a towel between his neck and shoulder as previously advised, difficulty stretching his hands and that because he was now so weak, it was difficult to dress him. The GP carried out a home visit on 20 May 2022, when the aunt and personal carer discussed their concerns about Brandon losing weight over time and that they had noticed that recently he had stopped opening his mouth when offered food or drinks, which he had done previously. He had pressure ulcers on his shoulders, although these did not break the skin. Blood tests were requested to see if the cause of the weight loss could be determined. The GP had no concerns about the conditions in the home, but chased up the OT referral in respect of the pressure ulcers. The blood tests were received on 27 May which showed that he was iron and vitamin D deficient, so supplements were prescribed, but no elevated white blood cell count indicating infection. The GP requested a Quantitative Faecal Immunochemical Test. The OT chased up the spasticity clinic appointment in June, requesting an urgent review, which took place on 24 June with recommendations for further Botox and a neck cushion.

4.12. The finance deputy had contacted a number of care managers to take on Brandon's case in compliance with CQC requirements, and in June 2022 a new private case manager was appointed (funded through his compensation payments). She conducted a home visit for an Immediate Needs Assessment on 20 June, which raised concern that Brandon had become significantly malnourished and dehydrated and developed pressure ulcers which she felt were at risk of becoming infected because these were not dressed. There was a strong smell of urine in the property, and the accommodation was unclean/unhygienic. Urgent referrals were made following the Immediate Needs Assessment due to concerns about Brandon's weight, nutrition status, eating, pressure sores, and care provision.

4.13. On 22 June 2022, Neurohealth put in a care review request to NHS North Central London Integrated Care Board as this was overdue. On 23 June 2022, the care manager sent an urgent request to the GP for assessment and dressing by the district nurses immediately to prevent infection. She was concerned that Brandon had become significantly malnourished and dehydrated, not opening his mouth or swallowing food or drink and requesting authorisation for

a speech and language referral and developed pressure ulcers which she felt were at risk of becoming infected because these were not dressed.

4.14. Brandon attended UCL's focal spasticity clinic on 24 June 2022 for his scheduled appointment, accompanied by his aunt and personal carer. He was seen by a consultant neurologist and physiotherapist, who administer Botox to alleviate the stiffness in his neck and made recommendations for the OT team to trial new pressure care cushions. They were concerned that it was getting harder for Brandon's family/carers to maintain his current range of movement at home. They had not been maintaining previous suggestions of applying splints, mainly because they were difficult to apply. District nurses visited for an assessment on 24 June 2022 and noted significant deterioration in Brandon's condition, with Deep Tissue Injuries (DTI) to his right scapula, Category 3 to his left scapula and 7 x Category 1 DTI's down his spine. He had a Toto mattress turning system and all the relevant pressure relieving equipment in place, but was chairfast during the day and only going in his in bed at night. A Tissue Viability Nurse referral was made, which took place on 6 July.

4.15. A CICH senior district nurse visited on 26 June 2022 to assess Brandon and he was noted to have significant muscle mass wastage and was very underweight with bone protrusion. His personal carer explained that Brandon was due to have a peg feed inserted and was under the care of the dietician, stroke, neurology and spasticity team. All relevant pressure relieving equipment was noted to be in place. Brandon had Deep Tissue Injuries (DTI) to his right scapula, Category 3 to his left scapula and 7 x Category 1 DTI's down his spine, although all the relevant pressure relieving equipment was in place. Brandon was noted to be chairfast during the day and only going in his in bed at night. A Tissue Viability Nurse (TVN) referral was made. Care plans were completed with a plan for the patient to be seen three times a week for wound and pressure area assessment, and a SKNN Bundle and Walsall assessment were completed.

4.16. The GP spoke to the aunt on 27 June about the unexplained weight loss, and made a referral for testing for bowel cancer. The case manager arranged a private Speech and Language Therapy service to assess Brandon the same day to determine whether he was having trouble swallowing. Brandon's aunt reported that on occasion, Brandon would not swallow fluids or food (holding it in his mouth), sometimes would not open his mouth to drink and that sometimes his swallow reflex was delayed.

4.17. At the request of the case manager, CHC reviewed Brandon's care needs on 29 June 2022 and agreed that his personal health budget support plan should be substantially increased, to provide 'double-handed' care. Having attended the care review, the Camden Rapid Access Service (RAS) admitted Brandon to their caseload for to avoid hospital admission, due to the GP's concerns that his nutritional intake was poor. He was seen by RAS clinician, his vital signs were stable, but it was not possible to take a blood sample so a referral was made for blood tests and a urine specimen and Brandon was discharged from RAS, referring the case back to the GP for a home visit to obtain a urine sample and phlebotomy for a blood sample to be taken. District nurses continued providing wound care. The case manager contacted UCL's spasticity clinic on 30 June, enquiring what had been trialled from a splinting perspective.

4.18. On 1 July 2022, a private tissue viability nurse specialist (TVNS) assessment was scheduled for pressure sore management, who reported that Brandon was extremely thin and had cachexia (wasting syndrome) and he also was very contracted. This also noted that over the last 12 months, he has lost weight and developed muscle atrophy and had three pressure ulcers due to loss of subcutaneous fat. TVNS made a number of recommendations, including a dietician referral which was already being pursued. TVNS noted that the carers were not turning him nor using appropriate equipment. She specifically reported that she was concerned as Brandon was not being moved 2 hourly and had significant pressure ulcers, there was no evidence of slide sheets being used, and the Toto turning system was not being used when Brandon was in bed to prevent pressure sores. Pressure sores, until her intervention, were

untreated, and no pain relief was provided. She was concerned about care being provided by family members with no external oversight and that care delivery was not meeting Brandon's needs. There were significant postural and positioning needs that had been unmet for some time.

4.19. The case manager took the view that Brandon could no longer be cared for at home, and obtained agreement from the family for an in-patient assessment, resulting in a referral on 5 July 2022 to Wellington Hospital, a private hospital that provides specialist neurological care. On 5 July 2022, the Wellington Hospital's neuro rehab team reviewed Brandon and agreed that that investigations and assessments would need to be conducted as an inpatient, requiring a 4-week inpatient stay initially. The GP made a further request for a blood test the same day and tried to secure a visit from the Rapid Response team for further health checks, but they felt the hospital admission was likely to be harmful to Brandon due to the risk of hospital acquired infection and the TREAT team could not support an admission as they had exclusion criteria for those who need hoist transfers.

4.20. Unfortunately, Brandon's aunt had an accident on 5 July 2022 after the door of her fridge fell off and struck her, causing her to fall, hitting her head and hurting her pelvis. Although she wanted to continue caring for Brandon, one of the district nurses insisted that she needed to go to the emergency department and on examination she was found to have fractured her arm and pelvis, so she was admitted to hospital. Although family members offered to provide care, only the personal carer had received training to meet Brandon's care needs but could not provide this 24/7. Consequently, the Continuing Healthcare team from the North Central London ICB made urgent arrangements for a care agency (United Care) to provide care over the weekend from 8 July to relieve the personal carer, as an approved agency through its procurement framework.

4.21. The personalised health budget support plan prepared as part of Brandon's Continuing Healthcare provision was updated on 5 July 2022 and provided to United Care, but this was not detailed and did not, for example, include details of his pressure ulcer care, feeding or medication regimes. Although a more detailed care plan from 2017 was included in the bundle provided by the financial deputy, it does not appear that this had been updated despite the deterioration in Brandon's condition, and is not clear whether this was available to the Continuing Healthcare team or United Care.

4.22. Blood tests taken on 6 July 2022 indicated that Brandon had a normal white blood count but his neutrophils were slightly elevated (8.77 when the upper level is 7.5). An abnormal follow up was booked. On 6 July, a private neuro physio also came out to assess Brandon to see if there was any other equipment that would assist positioning and transfers due to lack of sufficient equipment provision. The physio attended to review Brandon while awaiting posture-specialist physio availability and made recommendations for specialist equipment to be purchased.

4.23. On 7 July 2022, Brandon was taken to UCL's Colorectal and General Surgery clinic by his personal carer and sister-in-law for a planned consultation, following the GP's referral in respect of his weight loss over the past year, despite continuing to eat and drink. The gastrological consultant assessed that he was not fit enough for a colonoscopy nor a CT virtual colonoscopy and was asymptomatic in respect of his bowels. Although they felt he would tolerate a CT scan, if this identified any abnormalities it was unlikely that he could tolerate any further investigation or treatment, so the consultant recommended that further investigations in respect of any bowel conditions were not appropriate. This was explained to Brandon's family, including his aunt and sister by telephone.

4.24. The case manager contacted the physiotherapist from UCL's spasticity clinic the same day, explaining that Brandon had been seen by several community teams in the past few weeks, and that concerns had been identified in respect of his posture and positioning, swallow, nutrition,

hydration and pressure ulcers. She advised that as his aunt had been admitted to hospital, the community teams recommended that in the interim, his care should be managed in an in-patient setting funded through his private funds allocated for his care. The physiotherapist recommended that the GP's views should be sought, but agreed that due to the complexity of Brandon's needs, he would best be supported by a multi-disciplinary team experienced at managing complex disability.

4.25. On 8 July 2022, the case manager sent an email to the ICB regarding private care provision, as Brandon had not had any ICB care provided since his aunt's hospital admission 3 days earlier. An urgent discussion about Brandon needing emergency care with ICB took place that morning and the ICB confirmed it would put urgent care in place. The private dietician visited 8 July, expressing her concern about Brandon being emaciated which was inconsistent with the carer's description of him eating well, with pressure ulcers, presenting in unclean clothes and the room being dirty. She did not hear wheezing in his chest, although she was close to measure his arm circumference. The case manager liaised with the GP about Brandon being admitted to Wellington Neurological Rehabilitation Centre, and convening a Best Interest panel.

4.26. The case manager made a safeguarding referral to Camden on 8 July, noting:

- Clinically significant weight loss (emaciated/malnourished/dehydrated)
- Significant pressure sores that were at risk of being infected as they were not being dressed/assessed by the district nursing team
- Potential swallowing problems that needed investigation
- Postural issues (due to positioning issues and equipment provision) that are contributing to pressures sores developing, being exacerbated, and not healing, as well as potential swallow issues the care package has recently broken down, as the main carer was admitted to hospital. There were significant concerns regarding Brandon's clinical presentation (as above) and the ability for the carers to provide adequate care that Brandon needed in addition to potential carer burnout, inappropriate manual handling and possible barriers to external intervention.

4.27. United Care started providing care to Brandon on 8 July 2022 and had a handover with Brandon's personal carer. That night, he was awake all night and this was relayed to his personal carer on 9 July. He had no nap that day and took a long time to eat or drink and was awake again most of that night. On 10 July, Brandon was awake all day and again, took a long time to eat or drink, holding liquids and food in his mouth. He was making an unusual sound and the carer asked his personal carer about this when he visited during the day, and he advised them to suction Brandon if he had aspirated food. Brandon's personal carer visited on both days, and told the carers that he usually ate and slept well.

4.28. District Nursing recorded that Brandon was visited by a senior community nurse on 10 July and his carers were present (although this does not specify whether this included the personal carer). A pressure ulcer assessment was completed. The carers did not report to have noticed any changes in his condition or having the need to escalate any changes. The timing of this visit is not recorded. He also had a Covid-19 vaccination.

4.29. United Care's logs indicate that Brandon hardly again slept that night, and on the morning of 11 July 2022, the agency carer noted that he was struggling to breathe. The personal carer reports that he was called twice by the United Care's carer on the morning, firstly because Brandon was having trouble breathing, then again because he had stopped breathing. He reports that he told them on both occasions to call an ambulance and started making his way to the house. However, during the learning event for the safeguarding adult review, United Care's manager reported that the agency carer was only able to speak with the personal carer once, then tried unsuccessfully to contact him a second time. The agency carer reported that she tried to call 111 for advice but could not get through (the safeguarding lead for the London Ambulance

Service reports that there is no record of a call to 111, but it is unclear whether this would have registered if the call did not connect).

4.30. The agency carer then reports that Brandon stopped breathing so she called 999. The London Ambulance Service has provided a recording of this call. The agency carer told the care handler that her patient had died 5 minutes ago, was not breathing and was a 92 year old male. The call handler asked whether there was a defibrillator in the house, which confused the carer. The call handler then gave the instructions to the carer about how to perform CPR.

4.31. When the ambulance arrived, they noted that Brandon's bedsheets had not been disturbed and that there was no evidence that effective CPR had taken place. The air mattress (required to reduce the risk of pressure ulcers) had not been deflated, which is necessary to perform CPR and there is a 'quick release' valve for this purpose. The carer gave the paramedics a medication chart which belonged to another resident of the house, presumably Brandon's 92 year old aunt (which may explain why she told the 999 call hander that he was 92).

4.32. There was a delay in starting CPR because the first ambulance crew to arrive assumed that a DNACPR would be in place due to Brandon's physical condition, and as they had been told he was 92 years old. When a second ambulance crew arrived, they advised CPR should be carried out, and basic CPR resulted in his chest rising (indicating there was no obstruction to his airway). However, due to his muscle contractions, Brandon's neck was at a difficult angle and on checking his airway by undertaking a laryngoscopy, a mass was removed from his oesophagus, which appeared to be food, although the agency carer reported that he had last been fed the previous evening.

4.33. After resuscitation attempted were unsuccessful, the ambulance staff recorded Recognition of Life Extinct at 09:30. The police attended due to the unexpected death. London Ambulance Services conducted an internal investigation which concluded that Basic Life Support (BLS) should have been started whilst details of the DNAR or palliative care information were sought, although it is not believed that the delay in commencing BLS would have changed the outcome in this case, due to the significant co-morbidities present and the likely ineffective CPR that took place prior to the LAS arrival.

4.34. In total, at least 30 minutes passed between the time Brandon stopped breathing and the ambulance service starting basic CPR. The Metropolitan Police Sudden Death report to the coroner made no reference to the item of food in Brandon's oesophagus, incorrect medication sheet and age being provided to the ambulance, or the delay in administering CPR. However, the postmortem completed by the medical examiner for the coroner found that he died of pneumonia with empyema (evidencing that he had pneumonia for some time) and complex neurological disorder, and also had heart disease and had recently had a stroke. There was no trauma to the throat indicating a choking incident and no food in Brandon's stomach, and none of the normal signs of choking were present.

4.35. The SAR process was suspended February 2024, to enable the Metropolitan Police to investigate concerns flagged by the London Ambulance Service that the agency carer may not have carried out CPR in accordance with the instructions of the 999 call handler, and that the agency carer provided a medication chart belonging to another resident (92 years old) to the paramedics, giving rise to concern the wrong medication may have been administered. The police investigation concluded that there was no evidence of negligence, as although the CPR may not have been effective, police had listened to the tape of the 999 call and there was evidence the carer was trying to follow instructions. The agency carer also reported that she given Brandon medication in accordance with the personal carer's instructions at the point of handover, and the only medication that was logged on the agency's medication log was Brandon's prescription, so the fact the wrong medication chart was provided to paramedics

appears to have been an error made in a stressful situation, which did not affect her care of Brandon. On the basis of these findings, the Care Quality Commission concluded its own investigation, allowing the SAR process to resume.

5. Legal framework

The Mental Capacity Act 2005

5.1. The provision of care and treatment is only lawful if the person receiving the care/treatment has either given capacitated consent or, if the person lacks capacity, acts are done in accordance with the legal obligations under the Mental Capacity Act 2005 (MCA) and the Human Rights Act 1998 (HRA).

5.2. Mental capacity is always decision specific, and professionals are expected to take steps to empower people to take decisions, for example by ensuring an appropriately calm environment and communicating in a manner that the individual can understand. The MCA sets out that a person lacks capacity in relation to a matter if at the material time they are unable to make a decision for themself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain, which includes conditions such as a traumatic brain injury. A person is unable to make a decision for themself if they are unable to understand the information relevant to the decision, to retain that information, to use or weigh that information as part of the decision making process, or to communicate their decision by any means. The fact that a person is only able to retain the information for a short period does not prevent them from being able to make the decision and capacity may fluctuate over time, for example as dementia advances people may have periods of lucidity and confusion. There is a presumption of capacity unless otherwise evidenced and a person cannot be treated as lacking capacity, merely because someone else considers their decision to be unwise.

5.3. The principles embedded in s4 MCA require that any decision taken on behalf of a person who lacks capacity to make it, follows the least interventionist approach, and is taken in the person's best interest. This is not just the person's medical best interest, but rather their welfare in the widest possible sense, considering the individual's broader wishes and feelings, values and beliefs. All decisions should follow careful consideration of the individual circumstances of the person and focus on reaching the decision that is right for that person – not what is best for those around them, or what the "reasonable person" would want. The person who lacks capacity to make a decision should still be involved in the decision-making process as far as is possible, and those who know them best should be consulted. The MCA specifies that this should include anyone the individual has named as someone to be consulted on the issue (often referred to as 'next of kin', although this phrase has no specific legal meaning), anyone caring for the person or interested in their welfare, the donee of a lasting power of attorney, and a court appointed deputy (collectively referenced as 'interested persons').

5.4. Section 4B allows that a person can be deprived of their liberty for the purpose of life sustaining treatment or treatment to prevent a deterioration in their condition in an emergency if there is a 'reasonable belief' (on the basis of 'reasonable steps' having been taken to establish) that the person lacks capacity to consent. Section 5 likewise sets out that acts of care and treatment will not incur liability if there is a reasonable belief that the person lacks capacity to consent being carried out, on the basis of 'reasonable steps' having been taken to establish that the person lacks capacity to consent to acts of care and treatment being carried out. In a fast-moving situation where professionals have limited information, and in circumstances where not taking action could endanger the person's life, the threshold for concluding that the person lacks capacity to consent to treatment is going to be low.

5.5. Section 9 of the MCA enables people to take a decision, while they still have capacity to do so, to appoint a Lasting Power of Attorney (LPA) to one or more individuals (the donees), to take decisions on their behalf if they lose the capacity to do so. This can either be in respect of their property and finances (which can take effect before or after the person loses capacity, depending on their wishes) or their personal welfare (which can only take effect if the person loses capacity to take decisions in respect of their own care), or both. This will only be legal if it is registered with the Office of the Public Guardian [OPG], and professionals are required to have sight of the registered document rather than relying on assertions by family members that this has been made. If an LPA is in place and the person loses capacity to take decisions in respect of their property and/or welfare, the donees have the authority to take those decisions on behalf of the individual, but only in accordance with the terms of the LPA and in the person's best interests.

5.6. Section 19 of the MCA also empowers the court to appoint a deputy to manage the property and affairs of a person who has lost the capacity to do so. The deputy is entitled to be reimbursed for reasonable expenses and, if directed by the court, to remuneration from the person's property for discharging their duties. Deputyships are overseen by the OPG to ensure that these are exercised in the best interest of the individual, and the OPG may require the deputy to file reports in respect of their expenditure. This oversight is relatively 'light touch' and the OPG is only likely to become substantively involved if there is evidence that a deputy or done if acting in breach of their fiduciary duties. It is important to note that in Brandon's case, although the court appointed a professional deputy to manage his property and financial affairs, which is common when a large compensation payment has been awarded, a personal deputy welfare was not appointed. Personal welfare deputies will usually only be appointed if the family is in disagreement about decisions in the person's best interest, or there are complicated decisions that need to be taken about an issue.

Do Not Attempt CPR

5.7. DNACPR decisions can be made by doctors in respect of their patients, with or without their consent, for example if the doctor believes that the person is unlikely to survive CPR due to their underlying health conditions or that CPR will cause the person more harm. Doctors have a duty to consult with the person, or if they lack capacity, with their interested persons. Case law has established that this consultation must take place unless to do so would cause the individual psychological harm[5] and there must be a compelling reason that it is not practicable or appropriate to consult with those interested in the person's welfare for a DNACPR to be made without consultation.[6]

5.8. A DNACPR that has been imposed by a doctor is setting-specific, and will only apply if the person moves to a new setting (for example, from home to a hospital or from hospital to a care home) if explicitly stated and should, in any event, be reviewed by a doctor in the new setting to ensure this remains appropriate in light of the person's current clinical progress. Recorded decisions about CPR should accompany the person when they move from one setting to another.

5.9. A DNACPR decision form in itself is not legally binding. The form should be regarded as an advance clinical assessment and decision, recorded to guide immediate clinical decision-making in the event of the person's cardiorespiratory arrest or death. The final decision regarding whether or not to attempt CPR rests with the clinical team responsible for the person's immediate care. In the absence of a valid DNACPR, paramedics will generally presume in favour of CPR in the event of a cardiorespiratory arrest, unless it would clearly not be in the

[5] *R (On the Application Of) v Cambridge University Hospitals NHS Foundation Trust & Ors [2014] EWCA Civ 822*

[6] *Winspear v City Hospitals Sunderland NHSFT [2015] EWHC 3250 (QB), [2015]*

person's interests, for example, if it appears that they have passed some time ago, or their injuries or health condition are so severe that they could not survive.

5.10. It is important to note that a blanket approach to DNACPRs and medical treatment (for example, automatically applying these to someone over a particular age or with a particular disability) is inconsistent with the principles of Mental Capacity Act 2005, the prohibition on discriminatory actions under the Equalities Act 2010 and the Human Rights Act 1998.[7] Everyone needs to have access to equal and non-discriminatory personalised support around DNACPR decisions and health care, that supports their human rights. However, no professional can be ordered to provide medical intervention which, in their view, is not appropriate, and there is no absolute duty to keep people alive, even if it is possible to do so.[8]

6. Analysis of Agencies' Actions

Competence in assessing people with brain injuries and opportunities to identify Brandon's declining health

This section will consider issues of training and competence in assessing people with a learning disability as a result of an acquired brain injury and complex physical and health needs; the issues that arose in relation to Brandon's feeding and effectiveness of information sharing and whether any agencies could have done anything differently to identify the reasons for Brandon's declining health at an earlier stage.

6.1. Brandon's health needs were undoubtably complex in particular due to his brain injury, and there was evidence that over time, his condition started to deteriorate. In light of the level of cognitive impairment that Brandon displayed, it was very difficult for clinicians to identify which parts of the brain had been impacted and how this was impacting him. Although there were periods when district nurses and other community health services were visiting the home, in particular, when Brandon had pressure ulcers, this was not consistent and there were extended periods when the family did not require outside support. Nurses sent an information sharing referral to Adult Social Care in 2015 after Brandon developed a stage 3 pressure ulcer, seeking a reassessment of his care and support needs. However, before this was completed, in December 2015, Brandon was assessed as being eligible for Continuing Healthcare, which meant that all of his health and care needs would be met by the CCG rather than Adult Social Care.

6.2. Brandon's posture and poor mobility also meant that his neck was becoming constricted into a downwards position, requiring Botox injections to try to alleviate the constriction and reduce the risk that he could aspirate fluids or food during feeding. Occupational health, speech and language therapists physiotherapy and nurses also gave advice to the family carers in respect of how to meet his needs.

6.3. In 2021, district nurses liaised with dieticians and contacted the GP surgery due to their concerns that Brandon had lost a substantial amount of weight. Practitioners noted that people who have significantly impaired mobility will often experience muscle loss, and this had been discussed with Brandon's family. However, it is common for people with serious brain injuries to develop cachexia, which is "*a multifactorial syndrome defined by an ongoing loss of skeletal muscle mass (with or without loss of fat mass) that cannot be fully reversed by conventional nutritional support and leads to progressive functional impairment*."[9] This is because the brain

[7] CQC report: Protect, respect, connect – decisions about living and dying well during COVID-1

[8] *R (Burke) v General Medical Council and Others* [2005] EWCA Civ 1003

[9] Fearon K, Strasser F, Anker SD, et al. (May 2011). "Definition and classification of cancer cachexia: an international consensus". *The Lancet Oncology*. **12** (5): 489–95. doi:10.1016/s1470-2045(10)70218-7. PMID 21296615

injury changes the metabolism, how the body copes with inflammation, and causes other changes to brain chemistry. This meant that although Brandon's aunt and personal carer were feeding Brandon a 'normal' diet (albeit ensuring that foods were soft and easily swallowed), he was progressively losing muscle and fat over time, and however much they fed him, he would not regain this weight. As he grew increasingly thin, his skin started to breakdown, which is likely to have accelerated his condition as cachexia can be exacerbated when people have pressure ulcers as these will 'leak' protein, which cannot then be replaced by the body.

6.4. Practitioners noted the difficulty in accurately weighing someone who cannot stand unsupported. CNWL's dietician service conducted a remote assessment in May 2022, when the family provided a mid-upper arm measurement of 23cm, which would give an approximation at the lower end of a normal weight. However, such measurements can be unreliable, particularly when provided by laypeople, who may not be measuring the right point on the arm, and the dietician service acknowledged that, despite current pressures on their service, it was essential to carefully consider whether a remote assessment will be appropriate in a specific case. The clinician also discussed Brandon's diet with his aunt and personal carer, advising that as there was a 12 hour gap between dinner and breakfast the next day, they would need to feed Brandon an additional late evening meal, to prevent further weight loss.

6.5. However, the most common cause of cachexia is cancer. This was investigated twice in 2022 after Brandon's aunt sought advice from the GP in respect of Brandon's continued weight loss and frailty. In February 2022 Brandon was noted to have blood in his urine, so a referral was made to UCL's urology department to investigate possible bladder cancer, but no abnormalities were found. In May 2022, the GP suspected bowel cancer, so referred him for an assessment through UCL's colorectal clinic. Just 4 days before his death, Brandon was taken to hospital for a colonoscopy which would have required general anaesthetic, but the consultant took the view that due to Brandon's frail condition, the risks of the anaesthesia were too great, and that in any event, it would not be in his best interest to undergo treatment for cancer if this was diagnosed. Consequently they did not carry out the planned procedure and referred Brandon back to his GP to monitor and assess him. This meant that the most likely cause of the deterioration in Brandon's condition had not been ruled out, and in the absence of clear symptoms of any other illness, the primary hypothesis for his condition remained cancer.

6.6. During the postmortem, the coroner discovered that Brandon had suffered a recent stroke which was likely to have occurred within the past few months, although the exact timing of this could not be determined. Brandon's family had not noticed any change in his condition, and this was not apparent to the healthcare professionals working with him in the community. However, this may have made it more difficult for Brandon to swallow, placing him at greater risk of aspirating food or fluids. This in turn, placed him at increased risk of developing pneumonia. Again, evidence from the postmortem indicates that this had been present for some time, as he had developed empyema, but the exact timing cannot be established.

6.7. Usually when someone has pneumonia, they will show symptoms such as coughing, chest pain and high temperatures. For someone with empyema, it would be expected that their fever would fluctuate up and down daily as infection periodically entered the blood stream, and blood tests would show very a high white blood cell count, as the body tried to fight off the infection. However, both Brandon's personal carer and GP commented during discussions with the author that Brandon's cough reflex was impaired both by his brain injury and the Botox injections he needed for his neck contractions, and he was not able to verbalise any discomfort. The GP who visited Brandon in May 2022 examined him and listened to his chest, noting that he was quite stiff, but not any unusual noises, and the private dietician who visited on 8 July also confirmed that she had not noted any concerns about his chest or breathing.

6.8. Throughout Brandon's medical records from 2016, there was no record that he had ever had a fever, and during the learning events a neurological specialist explained that in cases of severe

brain injuries, the function of the hypothalamus can be impaired, meaning that the person will not run a temperature when unwell. The agency carer had taken Brandon's temperature twice on the night of 10 July, and these were recorded as 37.2 and 37 degrees, a normal temperature. Blood tests taken in May did not indicate that Brandon had any infection and another blood test on 6 July (5 days before his death) indicated that Brandon had a normal white blood count but his neutrophils were slightly elevated (8.77 when the upper level is 7.5), so a further blood test was booked to establish the reason for the abnormal result. However, these were not the extremely high white blood cell or neutrophil levels that would be expected for someone with pneumonia with empyema. It therefore appears likely that Brandon's brain injury was affecting him in ways which masked the usual symptoms of pneumonia, making it extremely difficult for doctors and other medical professionals to diagnose him. One of the GPs commented to the author "*Nothing from a clinical perspective was adding up."*

6.9. When the Neuro Health case manager was privately commissioned by Brandon's financial deputy and carried out an immediate needs assessment on Brandon on 20 June 2022, she was extremely worried about his presentation. She immediately arranged urgent referrals in relation to his swallow, potential risk of aspiration, his excessive weight loss over the past 2 years and significant pressure sores on his back that were at risk of being infected. There were also concerns around Brandon's postural issues and equipment positioning, these issues were likely to be contributing to his pressure sores not healing. The case manager arranged an urgent Tissue Viability Nurse (TVN) referral and Brandon was seen by the TVN 1 July 2022, and he was noted to have a grade 3 pressure ulcer on his scapula and 7 grade one pressure ulcers down his spine, indicating skin failure at end of life (SCALE). The case manager made referrals to the Neurology Team's Physio and Speech and Language therapist, they carried out their visits on 27 June 2022. The Neurology Team also had safeguarding concerns about Brandon's posture and the way his weight loss was presented with when they saw him. The Spasticity Team were already involved with Brandon and were reviewing him regularly to address his postural issues, all the other referrals were made as part of the initial needs assessment. The Spasticity Team coordinator also raised concerns about Brandon's condition on 24 June 2022, stating that they were shocked at the state he was presented in, highlighting his likely lack of nutrition and postural issues. However, Brandon's GP told the case manager that she did not have any safeguarding concerns in respect of the family, and felt that they had been proactive in seeking medical care for him. During Brandon's care review on 29 June 2022, it was decided that his care provision would be increased and that another directly employed carer (most likely another family member) would be hired. Due to her concerns that Brandon's needs were not being met by the family carers, the case manager made a safeguarding referral to Camden's Adult Safeguarding team on 8 July 2022 (discussed further below).

6.10. The CHC team sought emergency approval for an increase to his personal health budget on 1 July 2022 to fund a second personal carer, on the basis that Brandon's condition had deteriorated and his aunt was becoming more frail and had been advised during the care review that she should not participate in moving and handling tasks. On 5 July, Brandon's aunt was admitted to hospital, and CHC urgently arranged for United Care to provide agency carers over the weekend to relieve the family personal carer, starting on 8 July 2022. The family had not been happy about this arrangement, as they wanted to arrange another family to provide the care, however, this was not agreed by CHC as no other family members had undertaken the mandatory training required to be paid as a personal carer through a PHB. In parallel to this care arrangement, the case manager was making enquiries of specialist neurological care hospital, which the family had reluctantly agreed to.

6.11. While it is unclear whether this worsened his condition, it is important to note that Brandon received his Covid-19 vaccination the day before he died, when this should not be administered to people with an existing chest infection. Even without clinical knowledge that Brandon had pneumonia, it would have been helpful for the agency carers to be made aware of any symptoms they should be alert to as a result of normal side effects of the vaccination, given his frail state.

6.12. As Brandon had never had carers from a private agency or respite care since moving to live with his aunt, CHC's PHB support plan for him lacked detail in respect of his feeding and nutritional requirements or medication. The personal carer provided a verbal handover to the agency carer and provided a handwritten note setting out Brandon's daily care needs, but advised that he did not have a log for food or fluids. In conversation with the author, the personal carer reported that in the preceding days, Brandon had not required suctioning and had been eating and drinking as usual. He was conscious that the agencies carers were not familiar with Brandon and made himself available over the weekend, including telephone calls and visiting the home for appointments with health professionals. The agency carers had also spoke to him on 10 July, advising that Brandon was "*a bit wheezy*" and off his food, so he told them to use the suction machine to remove any mucous from Brandon's lungs.

6.13. It is extremely unfortunate that Brandon's condition deteriorated immediately after the agency carers started caring for him, as they were unfamiliar with his usual presentation and therefore were not in a position to recognise that he had taken a turn for the worse. Although they were concerned about his lack of appetite, refusal of fluids and wheezing lungs, they felt reassured by the personal carer's advice and presumed that this was Brandon's normal presentation.

6.14. However, on the morning of 11 July, Brandon's condition had seriously deteriorated and he was struggling to breathe. The personal carer reports that he was called twice by the United Care's carer on the morning, firstly because Brandon was having trouble breathing, then again because he had stopped breathing. He reports that he told them on both occasions to call an ambulance and started making his way to the house. However, during the learning event for the safeguarding adult review, United Care's manager reported that the agency carer was only able to speak with the personal carer once, then tried unsuccessfully to contact him a send time. The agency carer reported that she tried to call 111 for advice but could not get through (the safeguarding lead for the London Ambulance Service reports that there is no record of a call to 111, but it is unclear whether this would have registered if the call did not connect).

6.15. The agency carer then reports that Brandon stopped breathing so she called 999. The London Ambulance Service has provided a recording of this call. The agency carer told the care handler that her patient had died 5 minutes ago, was not breathing and was a 92 year old male. The call handler asked whether there was a defibrillator in the house, which confused the carer. The call handler then gave the instructions to the carer about how to perform CPR, however, when paramedics arrived, they noted that Brandon was still on his inflated air mattress, with the bedding undisturbed.

6.16. It is vitally important that agency carers feel confident to call 999 without delay if someone in their care becomes seriously unwell, in particular if they are struggling to breathe, having chest brain or showing signs of a stroke. They should also receive basic first aid training, including CPR techniques. United Care's Emergency Situation Guidelines for its carers does advice that in emergency situations "*such as falls and accidents*", staff should call 999, but the guidance is 5 pages long and somewhat confusing, noting at another point that if a service user becomes ill, United Care's office should be contacted initially for advice, and that if they "…*find a service user who is apparently 'dead'*" they should call 999 and not touch the body. This does not clarify that CPR should be initiated if the person has only just stopped breathing or cardiac function.

6.17. Although the agency carer had attended a basic first aid training course, she had not given CPR previously, and was not given advice by the 999 call handler to deflate the air mattress. The handler did suggest she move Brandon off the bed, but the carer could not do this alone. It is acknowledged that this was an extremely stressful situation, and that to be effective, CPR requires a good technique. Although she could be heard following the instructions of the 999 handler during the call, there was then a lengthy gap in CPR when paramedics arrived, as they had been told that Brandon was 92 years old (as the agency carer had become confused during the 999 call) and in light of his emaciated condition, believed that a DNACPR would be in place,

so took the time to search for this. It was only when a second paramedic crew arrived that a decision was taken to attempt resuscitated. Although it is highly unlikely that Brandon would have responded to this, given his advanced pneumonia and significant co-morbidities, the London Ambulance Service have acknowledged that basic life support should have been started whilst details of the DNACPR or palliative care information were sought. The decision could then have been passed to the senior clinician on call to take a decision about whether resuscitation was viable. This learning has already been taken forward by the London Ambulance Service.

Systems finding

6.18. Brandon's brain injury impacted on his health and physiology in a number of ways that could mask other health needs, making it very difficult to diagnose him or recognise changes in his condition. Although appropriate referrals were made to individual health services for investigation and treatment of each symptom identified, this approach was 'episodic' and reactive. Regular multi-disciplinary meetings to explore the observations of Brandon's presentation by frontline practitioners and family carers, supported by expert advice from his neurological specialist team would have promoted a holistic understanding of his needs and facilitated support and contingency planning. The PHB support plan provided to the commissioned care provider did not reflect the complexity of his needs and as a result agency carers were not equipped to recognise the deterioration in his condition. Although it is unlikely to have prevented Brandon's death, gaps in training and guidance for the 999 call handler, paramedics and agency carer meant that effective CPR was not promptly provided.

Recommendation 1: *The ICB and Adult Social Care must ensure that people with complex neurological conditions have regular multi-disciplinary assessments and reviews including a clinician with expertise in neurological conditions when involved, to consider their holistic needs and the interaction of their co-occurring conditions. If the individual is not open to neurology, but has symptoms which are difficult to explain, GPs should make a referral to neurology for advice. This should be used to prepare treatment plans, care plans, PHB support plans and contingency plans that provide proper guidance to frontline staff in recognising and meeting the individual's unique needs. Where the individual has privately funded health or social care providers, they should be invited to contribute to the assessment/review, and the outcome should be shared with any LPA donee or a court appointed deputy in respect of their finances or welfare.*

Recommendation 2: *Training/guidance for 999 call handlers should include advice that if the individual uses an air mattress, this must be deflated before CPR commences.*

Recommendation 3: *Commissioners should ensure that commissioned care services have clear procedures in place to support staff to respond to emergency situations, checking these for clarity and ease of use.*

Multi-agency commissioning and oversight

This section will consider how the system and multi-agency arrangements for services for people with complex needs are commissioned and managed on a multi-agency basis, including the interface between continuing health care (CHC) and the Office of the Public Guardian and role of paid carers when they are also family members.

6.19. Brandon's health and care support was commissioned through a number of different funding streams through the years, privately through the court appointed deputy managing his compensation fund, and through public funds by Camden Adult Social Care (for a short period in 2016) or NHS Continuing Healthcare from December 2016, when Brandon was assessed as being eligible for this. Although agencies were responsive when the family reached out for help, the source of the funding was opaque to practitioners, which meant that agencies were not clear

about who was accountable for overseeing the services commissioned. Many health practitioners were unaware of the involvement or role of the finance deputy and the fragmented funding streams created some obstacles to a coordinated approach to understanding and meeting Brandon's needs.

6.20. The NHS National Framework for Continuing Healthcare (CHC) determines whether an individual is entitled to a package of ongoing care that is arranged and funded solely by the NHS where the person has complex ongoing healthcare needs that are a 'primary health need'.[10] Managers commented that CHC could be perceived as a funding stream as opposed to the person-centred approach to meeting the needs of the most vulnerable people in society espoused in the National Framework. There are overriding rules that the NHS should never subsidise private care with public money, and patients should never be charged for their NHS care, or be allowed to pay towards an NHS service.[11] The CHC Framework [from para. 294] sets out that the NHS care package provided should meet the individual's assessed health and associated social care needs as identified in their care plan, and that if they wish to purchase additional private care or services, the reasons for this should be explored, including whether this is because the person or their family do not consider the existing package to be adequate to meet their needs.

6.21. The CHC Framework [para.201] requires CHC care plans to be reviewed within 3 months of the eligibility decision being taken, then at least annually, or when there is a change in the person's health needs. However, CHC infrequently reviewed Brandon's case, with his 3 month review taking place 11 months after the eligibility decision, a 21 month gap until his second review, and his third review did not take place until January 2021, when his care needs were assessed to be stable, which triggered a referral for a full CHC reassessment, but this was not completed due to the availability of the CHC clinician. Leaders noted that because he had been originally assessed as being eligible a personal budget from the local authority before he was assessed as being entitled to CHC in 2015, his case was managed on LBC's Mosaic ICT System. Although the CCG was tracking CHC cases that had transferred in this way, the full case records had not been migrated over and his Personal Health Budget (PHB) was being paid by the local authority and recharged to the CCG. This limited management oversight of the case. ICB leaders reported that the introduction of the CareTrack system in 2023 provided a report of the frequency of CHC reviews to NHS England. At that time, the ICB was up to date with all CHC reviews, although leaders noted that generally these were conducted by the CHC nurse, rather than a full multi-disciplinary assessment.

6.22. Practitioners commented that the fact Brandon's care was funded through a PHB created difficulties in overseeing the care and support he was receiving from his personal carer. A PHB is an amount of money to support the person's identified healthcare and wellbeing needs, which is planned and agreed between the individual or their representative, and the local ICB. Personal Health Budgets are intended to provide the individual with more choice and control to meet their needs [para. 320 of the CHC Framework]. However, because people are able to arrange their care through family or friends, many of the safeguards and monitoring mechanisms in place for CQC regulated care providers, such as care, nutrition and medication logs are not available.

6.23. The financial deputies noted that the family were resistant to having a case manager to oversee Brandon's care, having been confused and resentful about the role of the original case manager, taking the view that they did not need additional supervision. The deputies wrote and spoke to the family on a number of occasions to encourage them to reinstate case management. The financial deputies noted that the role of the CQC with respect to individuals employed as personal carers lacked clarity, but explained that after the British Association for Case Managers

[10] https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care
[11] Guidance on NHS patients who wish to pay for additional private care

approached the CQC for clarity on this issue in 2020, professional deputies had now taken the view that they were required to commission a CQC registered professional to oversee the package of care, so that they could ensure compliance with safeguarding and monitoring care provision. They advised the family of this in late 2021 which the family refused, and in March 2022 the deputies wrote again, explaining that Brandon would not be eligible for a personal budget without oversight of a case manager. The family then agreed, resulting in the instruction of the new case manager in June 2022.

6.24. Although the financial deputies noted that they had been informed that funding for the personal carers had been taken over through the personal health budget, they were not told that Brandon had been assessed as eligible for CHC and were not aware of any of the NHS professionals who were supporting Brandon. They were not made aware of the concerns that had started to arise from 2015 in respect of Brandon's pressure ulcers and weight loss as they were reliant on feedback from the CCG (now ICB), but felt that they could have worked collaboratively with the professional network to encourage the family to engage with support. This would be of particular importance in cases where the personal carers were privately funded, as the financial deputy would have a responsibility to ensure that their client was receiving good value for money. The strength of a multi-agency approach could be seen from the way practitioners were able to progress decision making during Brandon's care review on 29 June 2022, which was attended by both NHS and private health professionals involved with Brandon.

6.25. The issues identified by the financial deputies in respect of their difficulty in understanding which professionals and agencies were involved in supporting Brandon, were mirrored by ASC (discussed further in respect of safeguarding below). Likewise, although examples of good practice and effective information sharing were identified, leaders explained that there were often barriers to effective communication between private healthcare providers and NHS providers. While regular multi-disciplinary assessments in accordance with Recommendation 1 above will go some way to connecting the professional network, partner agencies across Camden need to embed a Team Around the Person ethos to support effective communication across the organisations involved and improve care coordination and safeguarding. Consideration will need to be given to the most appropriate way to establish a 'directory' of agencies/practitioners involved, which can then be accessible to other agencies. For example, one leader suggested adoption of a 'neighbourhood' model to promote shared multi-agency care plans with all relevant care plans in one place and accessible to other agencies.

Systems finding

6.26. Although information sharing and coordination of care was generally effective between NHS services when concerns arose, Brandon's care was not proactively managed through adherence to the requirement to hold regular multi-disciplinary Continuing Healthcare reviews. Other partner agencies such as ASC, the court appointed financial deputy and privately funded health practitioners were disconnected from the professional network, resulting in poor communication, duplication and inconsistent oversight of the package of care. This was remedied by the robust response by the case manager when appointed in June 2022

Recommendation 4: *Health and social care partners should provide guidance to practitioners conducting assessments and reviews of CHC or care and support to ensure that any support plans clearly identify funding streams (both privately and publicly funded) for different elements of support and who is responsible for overseeing this, to improve accountability for commissioned services.*

Recommendation 5: *Partner agencies should develop a policy or review existing policies to promote a Team Around the Person approach to improve communication pathways for frontline practitioners and commissioners, including any privately funded health or care providers, as well as family members, deputies or LPA donees, and improve coordination and*

delivery of health and care.

Recommendation 6: *CSAB should discuss this review at regional level and (if regional leads are in agreement), escalate to national SAB chairs network:*

a) *Whether the SAB chairs network should make submissions to the Casey Commission in respect of the impact of fragmented funding streams on those with complex health and social care needs, and the need for this to be resolved to improve outcomes and accountability when commissioning care.*

b) *The risks that emerged in this review due to gaps in CQC regulation and guidance with respect to personal carers employed through PHBs and personal budgets, with a view to raising this with the CQC and Secretary of State for the Department for Health and Social Care.*

Recommendation 7: *The ICB should provide an assurance report to CSAB in respect of its current compliance with timescales for CHC assessment and reviews, including whether reviews are drawing on the Team Around the Person.*

The role of family carers

This section will consider the role of family members and informal carers and statutory carers assessments and consider how carer strain and safeguarding needs are identified

6.27. Section 10 of the Care Act 2014 gives anyone who is looking after another adult with care and support needs the right to a carer's assessment. These assessments should address the carers' mental and physical health, their ability and willingness to care, and their relationships with others. Section 9 of the Care Act 2014 clarifies that an assessment of a person's eligibility for care must consider all of the person's care needs, regardless of any support being provided by a carer, and that this informal care must not influence the eligibility determination. In addition, s20 places a duty on local authorities to meet carers' needs in accordance with a national eligibility threshold.

6.28. The CHC Framework [at para 352-3] sets out that when an ICB is supporting a home-based package where the involvement of a family member or friend is an integral part of the care and support plan, it should agree with the carer the level of support they will provide, and may need to offer additional support to allow the carer to have a break from caring responsibilities. Carers should be made aware of their existing rights to an assessment and support of their own needs, including those rights under section 10 of the Care Act 2014. Practitioners noted that ASC will now notify Camden Carers when cases involving informal carers were transferring from ASC to CHC, to ensure that carers could access independent advice in respect of their entitlements. It is important to ensure that this includes both cases when the informal carers are already known to and engaged with Camden Carers and any new referrals by ASC to Camden Carers. Equally, it is important that in cases when carers have initially declined support, they are provided with information about how to revisit this at a later point, as their circumstances or willingness to accept support may have changed.

6.29. Clinicians from the GP surgery, district nurses and tissue viability nurses who supported Brandon over a number of years were very positive about the family's ability to meet his needs, and clearly held enormous respect for his aunt and her dedication to Brandon. During learning events, they reported that they had no concerns about the conditions of in the home, and felt that Brandon's aunt and personal carer had been proactive in seeking advice and treatment as health needs emerged over time, including seeking medical advice about his low weight and poor condition in May 2022.

6.30. Health professionals also gave advice to the family carers in respect of nutrition and feeding, the importance of ensuring that Brandon was sitting correctly in his chair or wheelchair, that they used hoists and splints and carried out daily exercises to help his posture. Although NHS practitioners were not confident that these were being carried out consistently, they felt that the aunt was seeking advice and trying to comply with this. However, some of the practitioners, in particular those who became involved in June 2022 were concerned that although the family desperately wanted to continue to care for Brandon as they always had, they did not have the knowledge or training to meet his complex needs. It seems likely that over time, Brandon's needs had gradually increased to the point that it would have been very difficult for anyone to prevent him from deteriorating outside a specialist neurological care centre. However, Brandon's aunt was deeply insulted by the suggestion that she was too old or frail to care for Brandon, and some practitioners may have been reluctant to cause her offence. There was no clear analysis of whether she and the personal carer understood and had the skills to meet Brandon's current needs, nor the risks to Brandon if his needs could not be met by his carers. One of the practitioners explained during the learning event that the family appeared to have 'change blindness' as they were not recognising the change in his presentation and wanted to continue caring for him in the way they always had done. It was vitally important for Brandon's needs to be kept under careful review as there was clear evidence that these were rapidly escalating.

6.31. The extent of Brandon's brain injury and the fact he was non-verbal appears to have result in a 'blanket' presumption that he lacked capacity, and that his family would make decision on his behalf, and it is clear that practitioners believed that his aunt had his best interests at heart. However, there were references in some of the documents from agencies to his aunt holding a lasting power of attorney, which cannot be correct, as Brandon suffered his brain injury prior to the introduction of the MCA and could not realistically had had capacity to sign and register and LPA. It is not uncommon that family members will not understand what is being asked of them when professionals ask if they hold an LPA, so practitioners should always ask to see a copy of the LPA, or request a copy of this from the OPG.

6.32. Brandon's financial deputy reported that Brandon's family were often reluctant to accept additional support funded through his compensation payment, even when specialists they had funded had recommended this as being in Brandon's best interest. The fact that a formal mental capacity assessment was not completed was a missed opportunity to explore Brandon's best interests and in particular, to distinguish his best interests from the wishes and needs of his family in respect of the decision to refuse care and support. Whilst Brandon's aunt and other interested persons would obviously need to be consulted with as part of this process in accordance with the requirements of the Mental Capacity Act 2005, this would have facilitated a discussion about Brandon's holistic needs, including the clear benefit he received from remaining in a family setting and any risks that could arise if his family was unable to consistently meet his needs in the future. This process may also have better supported Brandon's family to understand the potential benefits of additional support, both for Brandon and his aunt in terms of reducing the impact on her, particularly as professionals felt that Brandon's needs were increasing and she was becoming more frail (although she disputed this). Further, a formal Best Interests process requires all of the realistic options to be explored in weighing the person's best interests, which may have supported practitioners to consider a broader and more creative range of support options, which may have better met Brandon's needs, or been more palatable to the family.

6.33. Section 42 of the Care Act 2014 places a duty on local authorities, with the cooperation of safeguarding partners, to make enquiries when there is reasonable cause to suspect that an adult in its area has needs for care and support (whether or not these are being met) which prevents the adult from protecting themselves against abuse or neglect they are experiencing or at risk of. If these criteria are made out, the local authority must make any necessary enquiries to decide whether any action should be taken and, if so, what and by whom. The threshold for

an enquiry of "reasonable cause to suspect" that the person is at risk is intentionally low, as it is often necessary to gather evidence to determine the cause of the concerns raised. As noted in the introduction, it is important that practitioners show professional curiosity when someone's health is deteriorating without a clear explanation, in particular when that person is non-verbal and wholly dependent on other for their welfare. While this was upsetting for the family, the care co-ordinator was acting entirely in accordance with her safeguarding duties in making the referral, in parallel with the urgent health referrals she made.

6.34. The safeguarding enquiry was an important opportunity to draw together the entire team around the person, to clarify what information each agency, including the private healthcare providers, held in respect of Brandon's condition and needs, and explore how his co-occurring health needs could impact on each other and mask other conditions. This was also an opportunity to assess whether Brandon's needs had progressed to a point where it was no longer possible for the family to meet these safely without specialist support. It is unfortunate that this referral was only made in the days before Brandon died, as the safeguarding process was just starting and a multi-agency strategy meeting had not yet been convened.

6.35. The local authority is able to delegate a s42 enquiry to another partner agency to carry out the investigation, if they are best placed to do so, but ASC practitioners felt that it was unclear who should take the lead in a safeguarding enquiry when the person's care was privately funding or provided through CHC. ASC noted that they had struggled to identify which agencies were involved with Brandon after the case manager made the safeguarding referral, as they had not been involved in the care review. Again, this reinforces the importance of establishing clear communication pathways through a team around the person approach before a health or safeguarding crisis arises.

Systems finding

6.36. Despite the distress caused to the family, the case manager acted appropriately in taking urgent action to draw together a multi-disciplinary health response and making a safeguarding referral to secure a multi-agency strategic safeguarding response. There is a gap in risk analysis in respect of cases where potential carer strain has been identified, with practitioners focussing on the carer's wishes but placing insufficient weight on the risk to the individual if the carer is unable to meet their needs, particularly if these are escalating. Insufficient consideration was given to the principles of the Mental Capacity Act 2005 and in particular, the importance of conducting mental capacity and Best Interest assessments in circumstances where an individual or family/carer is declining a service that may be necessary to meet the person's care needs.

Recommendation 8: *The ICB and Camden ASC should review CHC/care and support assessment forms to ensure that these support an express assessment of whether informal and family carers understand and are able to meet the person's needs without additional support. This assessment process may require provision of specialist training for paid and/or informal family carers. In cases where it is predictable that the individual's needs will continue to escalate, contingency plans should be incorporated in care plans to provide clear advice to carers on how to identify that needs are escalating, how to meet those needs safely (including refresher training) or to access timely and targeted support to address this.*

Recommendation 9: *Ongoing programmes by partner agencies to strengthen practice in respect of the Mental Capacity Act 2005 and Best Interest decisions should be used to reinforce that proportionate assessments and best interest decisions should be carried out and recorded in respect of all significant decisions about a person's care, in particular when a care package has been refused by the individual or their carer. The OPG should consider how to ensure that court appointed deputies are applying these principles in exercise of their duties, and how to support deputies to speak confidently to families about the use of compensation*

held on trust to meet health and care needs and improve the individual's quality of life.

7. Glossary

ASC	Adult Social Care
CCG	Clinical Commissioning Group
CHC	Continuing Healthcare
CNWL	Central and North West London NHS Trust
CSAB	Camden Safeguarding Adults Board
DoLS	Deprivation of Liberty Safeguards
DN	District nurse
DNACPR	Do not attempt cardiopulmonary resuscitation
ECHR	European Convention on Human Rights
GDPR	General Data Protection Regulation
GP	General practitioner
HRA	Human Rights Act 1998
ICB	Integrated Care Board
LBC	London Borough of Camden
MCA	Mental Capacity Act 2005
OPG	Office of the Public Guardian
OT	Occupational therapist
PHB	Personal health budget
RLH	Royal London Hospital NHS Trust
SAR	Safeguarding Adult Review
TVN	Tissue viability nurse
UCL	University College London Hospitals NHS Trust