

Hertfordshire Safeguarding Adult Board
Safeguarding Adults Review
Josanne Wadsworth
Overview learning report

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1. Executive Summary

- 1.1. On 11th January 2017 Josanne Wadsworth was admitted to Lister Hospital, Stevenage, further to pulling out her Percutaneous Endoscopic Gastrostomy (PEG) tube, to undergo a planned replacement procedure. Josanne was living at the St Elizabeths Centre, Much Hadham, Hertfordshire prior to her admission.
- 1.2. Josanne was a 31 year old female with a severe learning disability and who also suffered from epilepsy. Josanne required the PEG primarily for administration of anti-epilepsy medication and for nutritional purposes. She had attended hospital on several occasions before due to the severity of her seizures as well as having the PEG inserted.
- 1.3. A series of missed opportunities occurred during her 16 day stay in hospital resulting in the PEG procedure not being undertaken. Josanne was prescribed some of her anti-epileptic medication via intravenous route and some orally. From 18th January Josanne started to refuse oral medication and therefore was not receiving all of her anti-epileptic medication.
- 1.4. On 21st January Josanne started to have seizures and began vomiting and pulled out her intravenous cannula on 22nd January and again on 23rd January. Re-insertion was not successful until the afternoon of 24th January, when supported on ward by the Outreach Critical care team. By 23rd January the seizures became more frequent.
- 1.5. On 25th January Josanne developed aspiration pneumonia secondary to the seizures. Tragically, Josanne died on 26th January 2017 with the medical cause being recorded as aspiration pneumonia.
- 1.6. A coroner's inquest held in November 2017 found that Josanne died of natural causes, contributed to by neglect.
- 1.7. This review was commissioned by Hertfordshire Safeguarding Adults Board. The review seeks to understand the circumstances leading to Josanne's death.
- 1.8. Placing the experiences of those directly affected by the death of Josanne at the heart of the review it will seek to identify learning. Considering aspects of preparedness and responses that were effective and those that may inform future good practice and where necessary and appropriate, to advise on what steps might be taken to address any areas that may be strengthened or improved.
- 1.9. There was early and continued engagement and communication with Josanne's family throughout the process.
- 1.10. Josanne was known to and supported by a number of agencies in Hertfordshire. The review considers how well these agencies worked together prior to, and leading up to, her final hospital admission in January 2017 when sadly she passed away.

- 1.11. In addition, this report considers the contributing factors/conclusion of the Coroners verdict at the Inquest Hearing held on 17th November 2017 that Josanne 'died of natural causes contributed to by neglect'.
- 1.12. Consideration is given to the findings from the new safeguarding enquiry opened further to information gathered as part of the SAR process.

2. Summary of Learning Points

Whilst there were undoubtedly significant catastrophic failings during Josanne's final admission to hospital in January 2017, the review has also considered the care, support, actions and interventions in the months leading up to this final admission before Josanne's death. It was agreed in the Terms of Reference, set by the SAR panel, that the time period covered by the SAR review would be 1 April 2016 – 26 January 2017. The following themes and learning were identified from the review.

Communication and co-ordination:

- 2.1. There were many agencies and specialty services and/or interventions involved with Josanne and her care, each of whom sought to provide the best care and support to meet her complex needs. Learning has highlighted some 'silo' working with lack of clarity about who was leading on aspects of care, referrals, follow up and review.
- 2.2. A Multi-disciplinary (MDT) meeting was not triggered at any point despite changes in Josanne's health and wellbeing. An MDT, if convened would have ensured that all those involved in Josanne's care and welfare, understood all the interventions available and their roles and responsibilities as part of that.

Person centred care, approaches and planning:

- 2.3 Putting each individual and their needs at the centre of their care and decision making, promoting the opportunity to hear the persons voice even when they don't use words to communicate is essential for person centred holistic care. Having an 'About Me/hospital book or 'My Purple folder' is an effective mechanism to help hospital staff to understand critical needs as well as how best to communicate with a person with a learning disability. From a learning point whilst the 'My Purple folder' was in place for Josanne, this was not effective and utilised to its potential to benefit Josanne's care.
- 2.4 Implementing the Learning Disability (LD) flag. The process for 'flagging' that a person has a learning disability and may need additional support/reasonable adjustments needs to be explicit and 'everyone's' responsibility. Staff need ongoing learning disability awareness training to have confidence when supporting a person with a learning disability. This will promote person centred working and encourage curiosity to understand each individual's needs. Moreover, appreciate and facilitate continuity of care, trigger the asking of questions to understand the severity of individual conditions along with any critical procedures/interventions, and to make 'reasonable adjustments' as required.

Systems and processes:

- 2.5 There was a failure to effectively utilise the Mental Capacity Act and Best Interest Decision making processes (assessment and best interest decision making, consideration of and actions to ensure best interests and timely intervention, ensuring that those who knew J well were involved). This led to delays and a seriously compromised deteriorating situation for Josanne. The plan on admission

seemed clear but the relevant referral and booking of the theatre slot, along with early discussion with those who know Josanne well, in terms of best interest decision making as she lacked capacity, was delayed. Despite Josanne lacking capacity and refusing her critical medication there was a failure to consider an alternative plan. There appeared to be poor understanding of the requirements of the Mental Capacity Act and hospital procedure/process for consent when following best interests, which again delayed progress.

- 2.6 There is a need for increased awareness and understanding of the 6 Safeguarding adult principles, individual responsibilities within the care act as well as good understanding of the management process to report and respond to concerns/complaints including escalation.

In addition, there was learning identified that had already been actioned via the E&NH Trust Serious Incident action plan:

- A clear pathway for PEG procedures which describes actions by whom, when and process for escalation if delay or deterioration along with clarity as to who assumes the co-ordinating role, facilitates MDT discussions and senior decision making when a person with a learning disability with complex/multiple needs is admitted to hospital reduces risks of delay and gaps in care.
- Processes for inter-disciplinary and inter-departmental working established, recognition of and timely action for the deteriorating patient and mechanisms for escalation developed.

Ways of working:

- 2.7 Promotion of safe, high quality and effective care is the business of every staff member irrespective of where they work. Training/awareness, policies and procedures are only effective if put into practice. Learning from the SAR, SI and learning event found that poor understanding and failure to follow hospital policy and guidelines led to gaps in care, delays in progressing with a plan and failure to meet even the most basic of human needs. Josanne was admitted as an emergency admission with a plan to re-insert her PEG. Although an emergency admission, a plan was made to schedule Josanne for theatre for a planned and 'routine' but critical procedure to re-insert the PEG. Due to delays and gaps in care her health deteriorated significantly. The learning from Josanne's experience needs to be used to 'Step into the shoes' of each patient, as a collective opportunity to 'test' the person centred approach, think holistically about each patients' needs, facilitate and value understanding of a person with a learning disability from those who know them well; listening and hearing what is shared.

3. Josanne

In undertaking this review both the Independent chair and report writer felt that it was important to appreciate who Josanne was, what those who loved and cared for her liked and admired about her, what things were important to her as well as what things she needed support with. Therefore, this introduction to Josanne has been drafted following a meeting with her family, talking with staff and reading her person-centred plan.

Josanne was a much loved 31-year-old young lady who was part of a large family, having 3 brothers, 2 sisters as well as Mum, Step Dad, Dad and Nan. Josanne was happy and sociable, loved being with people- 'knowing them and being known' to use the words of her sister. She enjoyed being read to, art and craft, going shopping and out for meals with her friends, being outside, and singing, especially 'Happy birthday'. Josanne used some words and Makaton¹ to communicate.

Josanne had a severe learning disability, with complex epilepsy which, up until the last three years of her life, was resistant to treatment meaning that Josanne had frequent seizures.

After leaving school in 2004 Josanne went to St Elizabeth's College in a residential placement, returning home every weekend. Josanne subsequently moved into a bungalow within the St Elizabeth's grounds, where she lived happily for 12 years until her death.

In 2010 Josanne was paralysed following a series of seizures and used a wheelchair from this time. Josanne struggled to come to terms with the change in her life, but her family, staff at St Elizabeth's and art therapy helped Josanne to cope and accept this change and she was soon signing 'happy birthday' again!. In 2010 a 'best interest decision'² was taken for Josanne to have a Percutaneous Endoscopic Gastrostomy (PEG)³ inserted, primarily to ensure consistent intake of prescribed anti-epileptic medication due to severity of seizures and to supplement feeding as required as Josanne had periods of time when she would refuse to eat and drink following episodes of epileptic activity. The PEG is described as 'critical' to the management of Josanne's epilepsy.

In 2014 Josanne was admitted to hospital due to multiple seizures which led to *status epilepticus*⁴. During this admission Josanne was prescribed a newly licensed Anti-Epileptic medication and this along with other medications worked well for her and saw her seizure free from this point until her admission to hospital in January 2017.

¹ Makaton is a very simple language based on a list of simple everyday words, which uses speech, gesture, facial expression, body language, signs, symbols and words to aid communication, <https://www.specialeducationalneeds.co.uk/makaton.html>

² Best interest decisions- Under the Mental Capacity Act 2005 any act done or decision made for or on behalf of an adult assessed as lacking capacity must be done or made in their best interests.

³Percutaneous endoscopic gastrostomy (PEG) an endoscopic medical procedure in which a tube is passed into a patient's stomach through the abdominal wall, most commonly to provide a means of feeding when oral intake is not adequate.

⁴ Status epilepticus (SE) is a single epileptic seizure lasting more than five minutes or two or more seizures within a five-minute period without the person returning to normal between them. Status epilepticus is a life-threatening medical emergency particularly if treatment is delayed.

Josanne's family describe how her character had secured the affections of the other people whom she shared her bungalow with as well as staff and carers at St Elizabeth's Centre, and how she had enjoyed a good quality of life.

Josanne had a number of attendances at, and short admissions to the Princess Alexandra Hospital NHS Trust (PAH) during 2016, having pulled out her PEG tube over the weeks and months prior to her death. Josanne had been under the care of the Gastroenterology team at PAH for a number of years, however following a review by the surgical team at PAH in November 2016 a referral was made by Josanne's GP to the Lister Hospital, which is part of East and North Herts NHS Trust.

On 11th January 2017 Josanne was admitted as an emergency to the Lister Hospital having pulled out her PEG tube with the balloon inflated. The plan on admission was for Josanne to be reviewed by Gastroenterology and the endoscopy nurse with a view to have re-insertion of the PEG in Theatre under General Anaesthetic. Josanne was assessed as being physically well on admission, and in the first few days was eating and drinking small amounts and taking some oral medication. Poor communication led to significant delays in referral and progress with the plan, resulting in Josanne going without adequate nutrition and hydration for the entire period of her admission. Josanne was prescribed some of her anti-epileptic medication intravenously and some orally. It is documented that there were some difficulties with oral administration with Josanne consistently refusing oral medication from 18th January 2017. Tragically at no point during Josanne's admission was the PEG reinserted. There were difficulties with administration of oral medication from 18th January, a lack of consistent IV access from 22nd January and no consideration of alternative routes of administration until 25th January. It was at this point advice was sought from the Consultant Neurologist. Josanne was now experiencing multiple seizures, she also developed aspiration pneumonia⁵ and sadly died on 26th January 2017.

⁵ Aspiration pneumonia is a type of lung infection that is due to a relatively large amount of material from the stomach or mouth entering the lungs

4. Context of the Review

- 4.1 The Care Act 2014, requires Safeguarding Adults Boards (SABs) to arrange a Safeguarding Adults Review (SAR) if an adult (for whom safeguarding duties apply) dies or experiences serious harm as a result of abuse or neglect and there is cause for concern about how agencies worked together.
- 4.2 Hertfordshire Safeguarding Adults Board (HSAB) commissioned an independent author, to carry out this review. The author holds professional background in both Learning Disability and General Adult Nursing, with over 32 years' experience in the NHS. Since leaving the NHS the author has worked as an Independent Consultant carrying out work encompassing service review, review of arrangements for adult safeguarding, and SAR. The author is independent of HSAB and its partner agencies.
- 4.3 The purpose of SARs is '[to] promote as to effective learning and improvement action to prevent future deaths or serious harm occurring again⁶. SARs are not concerned with attributing blame and are not part of any disciplinary matter.
- 4.4 HSAB also appointed an Independent Chair for the SAR, Steve Holton, Area Commander, Hertfordshire Fire and Rescue Service.

⁶ Department of Health, (2016) Care and Support Statutory Guidance Issued under the Care Act 2014

5. Terms of Reference and Methodology

Terms of reference

The purpose of the SAR is to collectively review circumstances leading to the death of Josanne on 26.01.2017. To determine what the relevant agencies and individuals involved might have done differently that may have prevented Josanne's death. To advise partner agencies and the Hertfordshire Safeguarding Adults Board in the exercise of their function, of those aspects of the preparedness and responses that were effective and those that may inform future good practice, together with, where necessary and appropriate, to advise on what steps might be taken to address any areas that may be strengthened or improved.

- 5.1 The ToR sought to place the experiences of those directly affected by the death of Josanne at the heart of the review, ensuring that family members were involved throughout.

| Terms of Reference |
|--|
| 1. To consider all data and information available to identify any gaps and/or missed opportunities |
| 2. To consider whether agencies and inter-agency responses were proportionate and appropriate leading up to and at the time of the incident |
| 3. To consider whether the principles of the Mental Capacity Act and assessments were upheld. Were any 'best interests decisions' made and did this happen in a timely manner; |
| 4. To explore whether reasonable adjustments were made by agencies involved |
| 5. What advocacy support was in place for Josanne |
| 6. To consider any specific equality and diversity issues |
| 7. To explore how existing systems, protect people who may lack capacity and how effective are they, specifically around people with a learning disability |
| 8. Identify any areas of good practice. |
| 9. To establish whether there are any lessons to be learned from the case about the way in which local professionals and agencies worked together to safeguard Josanne |
| 10. To identify what those lessons are, how they will be acted upon and what is expected to change as a result. |
| To ensure that the management of JW's feeding tube is considered throughout all these areas |

The review has considered the period April 2016 leading up to Josanne's death in January 2017, in order to capture a full chronology relating to management of the PEG tube and to facilitate any learning in relation to care, wellbeing, interventions and support both in the community and in hospital.

Methodology

- 5.2.1 A SAR panel was established to support and inform the review.
- 5.2.2 The following agencies were represented/members of the SAR panel:
- East and North Hertfordshire and Hertfordshire Valley Clinical Commissioning Group (CCG), Head of Adult Safeguarding
 - Hertfordshire Adult Social Care, Head of Adult Safeguarding
 - St Elizabeth's Centre, Director of Adult Services and Clinical Services Manager
 - East and North Herts NHS Trust, Lead Nurse Adult Safeguarding
 - Hertfordshire Community NHS Trust, Named Nurse for Safeguarding Adults
 - Hertfordshire Safeguarding Adults Board, Safeguarding Board Manager
- 5.2.3 The SAR panel identified the review period to include April 2016-January 2017 and jointly agreed the Terms of Reference.
- 5.2.4 The Chair and Independent author met with Josanne's family which helped to understand who Josanne was, and give the opportunity to contribute to the review.
- 5.2.5 Josanne's family asked that her real name was used as opposed to a pseudonym throughout this SAR report.
- 5.2.6 The Chair and Independent Author are very grateful to the family for their input which they were happy to give and expressed their hope that this review will realise learning and improvements that can make a difference for others.
- 5.2.7 The SAR panel received a detailed chronology from all agencies along with Independent Management Review (IMRs)⁷ narrative reports. East and North Herts NHS Trust also provided the panel with their Root Cause Analysis (RCA)⁸ report and action plan.
- 5.2.8 Following review and analysis of the chronology, IMRs, RCA and action plan a learning event was facilitated with managers and frontline staff from all agencies to collectively consider learning to inform the drafting of recommendations for improvement.

⁷ IMRs are narrative reports completed by each identified agency responding to the Terms of Reference agreed within the SAR process

⁸ RCA is a method of problem solving used for identifying the root causes of faults or problems

6. Background

- 6.1 As described in section 3 of this report Josanne was a much loved happy young lady who was part of a large family. Josanne had a severe learning disability and epilepsy, used some words and Makaton to communicate. Josanne used a wheelchair after prolonged and significant seizures in 2010 left her paralysed.
- 6.2 Although able to eat and drink Josanne struggled to maintain sufficient nutrition, often refusing diet and fluids following episodes of epilepsy activity and also to take her medication. Therefore, Josanne had a PEG tube inserted in 2010 to ensure delivery of critical anti-epileptic medication and to supplement nutrition intake. Josanne received care, advice and support in relation to her PEG from the Community Nutrition and Dietetics Service, Hertfordshire Community NHS Trust and Abbotts specialist nurses.
- 6.3 Josanne had lived for 12 years in a bungalow with other people, with care and support provided by St Elizabeth's Centre, a specialist charitable organisation providing education, care and support for people with epilepsy.
- 6.4 Josanne received input from specialist nurses, known as Abbotts nurses, for advice and support with her PEG along with a Community Dietician.
- 6.5 In the weeks and months prior to her admission to hospital and subsequent death, Josanne had a number of hospital appointments, attendances and admissions. Initially for consideration of an alternative PEG site and/or an alternative mechanism/tube due to over granulated area around the site and in the 2 months prior to her last admission to hospital as a result of pulling out her PEG tube. All attendances, appointments and admissions up until 23rd December had been to The Princess Alexandra Hospital NHS Trust (PAH NHS Trust).
- 6.6 Further to a planned appointment with Endoscopy for PEG replacement at PAH NHS Trust, Endoscopy requested a surgical opinion and possible debridement of the Granuloma⁹.
- 6.7 Having reviewed Josanne's granuloma the Consultant Surgeon wrote to Josanne's GP advising that surgical intervention not required and therefore discharged back to Endoscopy.
- 6.8 Josanne had 3 attendances during November for PEG re-insertion. The third attendance resulted in admission for 5 days during which time a Radiologically Inserted Gastrostomy (RIG)¹⁰ tube was inserted for Josanne. In addition and prior to these attendances Josanne had pulled out the PEG tube on a number of occasions when staff at St Elizabeth's had been able to successfully re-insert the PEG tube at home.

⁹ <https://www.healthdirect.gov.au/granuloma>. A granuloma is a small area of inflammation tissue. It is caused by a collection of immune system cells, as a result of chronic inflammation.

¹⁰ Radiologically Inserted Gastrostomy is tube is described as a way of introducing food, fluids and medicines directly in to the stomach by inserting a thin tube through the skin and into the stomach

- 6.9 Following the insertion of the RIG Josanne was discharged back to Endoscopy. Further to the surgical review and discussion with Specialist Dietician in November 2016, Josanne's GP referred her to the Endoscopy Nurse Practitioner at Lister Hospital, East and North Herts NHS Foundation Trust.
- 6.10 Josanne had one attendance at Lister Hospital A&E in December following pulling out of RIG tube with successful re-insertion by St Elizabeth's staff. Attendance at A&E was due to concerns about possible internal bleeding. No concerns identified at the hospital and Josanne was discharged home.
- 6.11 On 11th January 2017 an ambulance was called as Josanne had pulled out her PEG tube, with the balloon inflated. St E's requested ambulance to attend Lister Hospital due to referral to Lister Hospital in November 2016.
- 6.12 Josanne was admitted to Lister Hospital as an emergency on 11th January 2017 with a plan to re-insert the PEG. Josanne was initially eating and drinking and taking anti-epileptic medications orally. It should be noted that not all of her prescribed anti-epileptic medication was available in the hospital via IV administration and St E's were not asked to bring her medication from home. From 17th January Josanne was kept Nil by mouth for prolonged periods of time in preparation for theatre. Josanne was 'listed' on the emergency theatre list on 20th January but this did not happen due to more urgent cases being given priority.
- 6.13 Poor communication, timeliness and clarity of referrals made, plus the lack of a clear plan led to numerous delays and failures in decision making and intervention which resulted in Josanne not having the PEG re-inserted at any point.
- 6.14 With no secure and consistent mechanism to administer the critical anti-epileptic medication or adequate nutrition Josanne started to deteriorate after 8 days in hospital. Attempts to administer fluids intravenously and nutrition via a Naso-Gastric tube were not tolerated well by Josanne.
- 6.15 Josanne started to have numerous seizures and was diagnosed with aspiration pneumonia and sadly died of a cardiac arrest on 26th January 2017.

7. Summary of Events

- 7.1 From the review chronologies and IMRs, events have been grouped into 3 key episodes.
- 7.2 **Key episode 1** covers the period **April 2016 - August 2016** and considers Josanne's community care, support and treatment in relation to her PEG site, over-granulation and infection. Despite the identified over-granulation around the PEG site and infection Josanne is described as being generally well and happy during this time.
- 7.3 During **April – August 2016** the skin around Josanne's PEG site was noted to be over-granulated, malodourous, with evidence of bloody and green discharge.
- 7.4 In early April St Elizabeth's (St E's) raised their concerns and those of the GP about the PEG site with the Abbott Nurse and Community Dietician, Hertfordshire Community NHS Trust (HCT). The Dietician recommended a Mic-Key G feeding Tube¹¹; this tube has a port that sits flush to the skin, the feeding tube is attached to the port therefore reducing the risk of it being pulled out as well reducing risks of infection and over-granulation.
- 7.5 Both the Dietician, Abbott Nurse, along with a colleague, visited and reviewed Josanne's PEG site and treatment advised with a follow up review planned for 2 weeks.
- 7.6 On review Abbott Nurse and Dietician recommended an appointment with the GP to seek referral for review by Gastroenterologist and possible re-site of PEG.
- 7.7 GP referral to Consultant Gastroenterologist at Princess Alexandra Hospital (PAH) **19th May 2016**.
- 7.8 St E's follow up the referral with GP **28th July 2016** and then with Consultant's secretary at PAH **4th August 2016**, who advised that referral passed to Dietician at PAH on **26th May 2016**.
- 7.9 Dietician contacted St E's on **5th August 2016** to advise referral passed to Endoscopy and appointment booked **12th August 2016**.
- 7.10 **12th August 2016** Josanne attended appointment with Endoscopy at PAH. Procedure not undertaken due to over granulated area and concern the existing PEG site will be difficult to heal. Request for Surgical opinion. **15th August 2016** letter to GP from Endoscopy Specialist Nurse, PAH requesting referral to Consultant Surgeons for opinion and possible debridement of the PEG site granuloma.

¹¹ Mic-Key G feeding tube: Is a low profile gastronomy feeding tube which allows a more active and mobile lifestyle.

- 7.11 PEG site reported to continue to be malodourous, with discharge. Swab shows Streptococcus Constellatus, GP notes indicate 'hold off antibiotics (past 6 months three courses appropriate antibiotics). Not unwell and no cellulitis'.
- 7.12 **24th August 2016** referral from GP to Consultant General Surgeon, Choose and book for appointment at PAH.
- 7.13 **Key episode 2** covers the period **September to December 2016** and considers interventions and actions following GP referral for Surgical opinion, appointment with Surgeon and discharge back to Endoscopy, referrals, appointments and emergency attendances.
- 7.14 **13th October 2016** Appointment with Consultant Surgeon PAH. Advised PEG re-site can be carried out by Endoscopy. Letter to GP states 'discharged back to Endoscopy'. Proposed re-insertion of PEG to new/separate skin entry point.
- 7.15 **3rd November 2016** St E's contacted Gastroenterology PAH re outstanding appointment for PEG re-site. Advised not enough information sent to Endoscopy. Endoscopy to contact St E's. **10th November 2016** St E's contacted Gastroenterology and message left enquiring about appointment for PEG re-site.
- 7.16 **12th and 13th November 2016** Josanne pulled cap/top off PEG-replaced by St E's.
- 7.17 **16th November 2016** Josanne pulled out PEG tube, attended A&E at PAH- PEG tube replaced by nutrition team. Noted to have Escherichia Coli urine infection, not clear if anti-biotics prescribed. Swab taken of PEG site with no significant growth.
- 7.18 **17th November 2016** New Corflo balloon gastrostomy tube inserted at PAH and Josanne returned to home to St E's.
- 7.19 **18th – 24th November 2016** Josanne was admitted to PAH having pulled out her PEG tube with balloon intact. Due to have PEG re-sited whilst an in-patient however, Consultant not happy to re-site and recommending an alternative device. Nutritional Practitioner PAH contacted St E's and Abbotts Nurse and emailed a report advising of Consultant recommendation. Communication between Abbotts Nurse and Dietician at HCT regarding admission and insertion of Corflo balloon Gastrostomy tube. Dietician suggested she would contact Multi Disciplinary Team (MDT) to discuss possibility of second opinion.
- 7.20 **25th November 2016** Dietician received an email from Abbotts Nurse, regarding re-siting of Josanne's PEG at PAH. The consultant had declined to re-site as he wanted to use Low Profile Gastrostomy Device (LPD), clinical rationale was that the Josanne was less likely to pull the LPD and this would cause less irritation and improve granuloma. Both Dietician and Abbotts Nurse expressed concern re LPD but acknowledged not another option currently.
- 7.21 **28th November 2016** Abbotts Nurse visited and reviewed stoma site and granuloma. Noted that granuloma much improved, plan to discuss LPD with Dietician. GP clinic appointment took place and copy of letter from Dietician taken. GP to refer to Lister Hospital East and North Herts NHS Trust (E&NH) Endoscopy.

- 7.22 **30th November 2016** GP referral to Endoscopy Nurse Practitioner at Lister Hospital, advising that Josanne recently discharged from Princess Alexandra Hospital and further to communication with Dietician, HCT.
- 7.23 **22nd December 2016** Dietician review- Granuloma remains much improved therefore LPD not indicated.
- 7.24 Referral from Consultant Surgeon at PAH to Upper Gastrointestinal Consultant at University College London Hospital, dictated 23rd December typed 5th January 2017.
- 7.25 **23rd December 2016** Josanne pulled out the Corflo balloon Gastrostomy tube, re-inserted on advice from Abbott Nurse. Stomach PH high therefore attended A&E at Lister Hospital. Returned home as PH normal. Abbott Nurse advised to monitor for 'Red flags' as detailed by the National Patient Safety Agency and to contact if concerns.
- 7.26 **Key episode 3 covers January 2017** emergency admission, treatment and intervention immediately before death.
- 7.27 **1st January 2017** Josanne pulls out Corflo balloon Gastrostomy tube at home, re-inserted at home.
- 7.28 **6th January 2017** Josanne pulled out gastrostomy tube, re-inserted at home.
- 7.29 **11th January 2017** Josanne pulled out gastrostomy tube with balloon inflated. Concern regarding possible internal trauma/damage therefore ambulance called. St E's staff requested Josanne to be taken to Lister Hospital E&NH NHS Trust due to referral to Gastroenterology/Endoscopy there. Josanne was admitted to the Short Stay Unit (SSU). Doctor (Gastro team) at Lister Hospital contacted St E's querying why sent in. Advised concern re trauma and infection. Doctor advised no trauma, CT would be required to identify internal trauma and this not warranted. Advised St E's of plan to re insert PEG and return with spares. Doctor also advised St E's to contact Gastro team that Josanne is under i.e. at PAH NHS Trust and get advice from them.
- 7.30 On admission to SSU Josanne's 'My Purple folder', sometimes known as a hospital passport or All About Me folder,¹² which contains important information about her needs including epilepsy guidelines and rescue treatment, medication and annual review were taken with her. Care staff accompanying Josanne advised hospital staff of Josanne's reliance on the PEG to receive critical anti-epileptic medication and sufficient nutrition. In addition one of St E's registered Specialist Epilepsy Nurses contacted SSU and reiterated the importance of Josanne receiving her anti-epileptic medication and noted not to have had a seizure since 2014 with current regime of medication delivered through her PEG. PEG tract noted to be closed with no sign of infection. Intra-venous (IV) access secured albeit with some difficulty, recommended that anti-epileptic drugs (AEDs) Keppra and

¹² The Purple folder contains important information that supports effective healthcare for people with a learning disability, <https://www.hertfordshire.gov.uk/.../my-health/my-purple-folder.aspx>

Phenytoin should be given IV and for those that could not be administered intravenously (Lamictal, Lamotrigine, Clobazam), encouragement should be given for Josanne to take these orally along with diet and fluids. Plan on admission stated to involve specialist PEG nurse and gastroenterology as soon as possible and 'list' for re-insertion of PEG. There was no 'alert' on the system indicating that Josanne had a learning disability. It should be noted that Josanne's 'rescue' protocol for management of seizures, which gives details of medication 'rescue treatments' for seizures, although taken into hospital as part of her Purple Folder, was lost within the notes. Midazolam, Clobazam and Paraldehyde, given in alternative formats to oral i.e. buccal and rectal were Josanne's 'rescue protocol medications'. These medications were not requested to be brought in from St E's.

- 7.31 **12th January 2017** Dietetics service informed of admission and referral to Gastroenterology completed. Food and fluids charts in place.
- 7.32 **13th January 2017** Consultant medical team ward round, noted to be taking medication and eating. Consultant noted 'given can eat and managing meds and recurrent dislodge of PEG for further review by nutritional team'. Referral to Dietician. Dietician visited Josanne in SSU. Advised ward team of need to consider nasogastric (NG) feeding as an interim measure - the patient will not meet requirements orally (only having around 500kcal/day), also very poor with taking oral fluids. Concern voiced by ward team that Josanne will pull this out and said Dr would like to try oral intake while the decision is made by the community team regarding long term feeding. Dietician confirmed that this is too long for the patient to wait on inadequate nutrition and may put the patient at risk of re-feeding syndrome ¹³.
- 7.33 **14th and 15th January 2017** (weekend) no medical team review. Oral fluids with thickener and nutrition encouraged, food and fluids charts stating refused food offered. Noted that food and fluid charts missing and/or poorly completed.
- 7.34 **16th January 2017** Dietician reviewed Josanne and noted poor oral intake over the weekend, refusing 'Build up' drinks. Dietician suggested NG feeding as interim measure again, encourage oral intake and high protein diet, expedite gastro review. High protein diet. No IV fluids given.
- 7.35 **17th January 2017** Reviewed by Gastroenterology team. Referral not received by Gastroenterology until 17/1/2017. It is unclear what happened to referral between 12/1/2017 to 17/1/17. Doctor contacted Josanne's Mother. Mother provided history of previous aspirations and chest infections, not good swallow reflex. Josanne's history of non-compliance with medications and food was discussed. Mother described that since 2010 epilepsy had been better controlled and improved quality of life with PEG. Best interest discussion with Mother as Josanne lacked capacity to consent to treatment. Plan for PEG insertion with General Anaesthetic. Anaesthetic review requested. Gastroenterology Registrar to discuss with

¹³ Re-feeding syndrome can be defined as the potentially fatal shifts in fluids and electrolytes that may occur in malnourished patients receiving artificial refeeding (whether enterally or parenterally). These shifts result from hormonal and metabolic changes and may cause serious clinical complications, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2440847/>

Endoscopy regarding PEG insertion. Doctor advised ward that procedure was likely to take place next day **18th January 2017** and therefore to be Nil by Mouth (NBM).

- 7.36 **17th January 2017** Specialist PEG Nurse receives referral generated on 12th January further to admission. Specialist PEG Nurse contacts Princess Alexander Hospital Endoscopy unit. PAH Endoscopy sister says Josanne had a RIG (radiologically inserted gastrostomy) inserted November 2017. PAH Endoscopy, did not have records of PEG insertion, advised Specialist PEG nurse to contact PAH dietician. Specialist PEG nurse notes state will contact ward on 18/1/17 with time and date of PEG/RIG. Josanne refused dose of oral medication.
- 7.37 **18th January 2017** PEG Procedure did not take place as Josanne was displaced on theatre list due to an emergency. Lack of capacity within system to carryout PEG procedure. Specialist PEG nurse and Gastroenterology consultant discussed and arrangements made for Josanne to be placed on the emergency list for 19/1/17. Josanne NBM ready for surgery. Plan for IV maintenance fluids. Documented that Josanne had missed 6 doses of anti-epileptic medication, no plan documented for alternatives.
- 7.38 Surgery did not happen **19th January 2017**. Josanne was placed on the emergency list for **20th January 2017**. Ward Sister contacted the 'operations team' to escalate that Josanne had been waiting for PEG insertion for 8 days. St E's staff documented raising concerns with hospital staff about Josanne's lack of diet and fluids, missed medication and the risk of seizures.
- 7.39 **20th January 2017** Surgery did not take place. Dietician review: 'Patient meant to go for PEG insertion today, taken off list due to urgent surgeries. It is documented that PEG is likely to be done on Monday (23.01.17). Staff Nurse reports the patient is refusing to open her mouth now, therefore, NG tube no longer appropriate. IV maintenance fluids, small amounts of oral intake. Dietician recommended that Josanne needs to remain an in-patient after PEG insertion to establish feeding regimen due to re-feeding risk'.
- 7.40 **21st January 2017** Josanne remained NBM with no plan for feeding. Josanne vomited and had a brief self-terminating seizure requiring oxygen. Episode of tachycardia and hypotension 14.30hrs. Josanne vomited a further 3 times after taking some oral medication. St E's raised concerns that Josanne looks weak, unwell, and is coughing. Advised ward again that Josanne is at high risk of seizures if not given her medication. Also advised she is high risk for aspiration pneumonia. Ward Sister arranged IV medications and requested Doctor checks chest. Serious Untoward Incident investigation identified that ward team not aware of Josanne's 'Seizure Intervention Care Plan' which details need for medication buccal midazolam 10mg should have been administered after the first seizure.
- 7.41 **22nd January 2017** Brief self-terminating seizure, productive cough- greenish fluid. Josanne pulled out her IV cannula after morning IV anti-epileptic medication and refused all oral medication. St E's again raising concerns, Josanne is very weak, has not slept and is coughing; escalating need for PEG procedure. Seen by Doctor

who advised St E's that hopefully procedure will happen tomorrow **23rd January 2017**.

- 7.42 **23rd January 2017** Incident form (Datix) submitted by Dietician regarding poor care on the ward, detailing refusal to trial NG tube for interim feeding; numerous occasions where procedure cancelled despite the fact the patient was on the emergency list; long periods of NBM. Result of NBM is high re-feeding risk. This risk is noted by the dietician as being 'preventable as the patient was not acutely unwell when admitted, and the reason for admission was for re-insertion of the PEG'.
- 7.43 **23rd January 2017** Following communication with Dietician at PAH where recommendation had been made for a Radiologically Inserted Gastrostomy (RIG) Low profile gastrostomy when tract formed, the Endoscopy team at Lister Hospital informed SSU staff to change request to RIG and to book procedure through Radiology. Multi-Disciplinary Team records stated RIG needed, but no plans evident in notes as to how this would happen. Subsequent Serious Incident investigation by E&NH NHS Trust identified that there was evidence of confusion about who was booking the theatre slot. Josanne still NBM (6 days) and oral anti-epileptic medication missed over previous 3 days. Evening of 23rd January Josanne has more frequent seizures, 7 self-terminating seizures. 23.36 hrs on call Doctor attends and both the Doctor and Critical Care Outreach Team (CCOT) nurses attempt to cannulate for IV access 10 times, no success. Anaesthetic team were called to assist but notes show still no cannula by following morning. Josanne suffered 5 further seizures overnight. Medical notes show plan that Josanne would have anti-epileptic loading dose when IV access established. St E's seizure termination plan was not followed.
- 7.44 **24th January 2017** 09.15 Josanne seen by Registrar and documented still no cannula in place. Vital signs showed tachycardia and pyrexia, chest clear. Rectal paracetamol given. Plan to ask Anaesthetists for central line, consent in terms of best interest discussed with family. Anaesthetist asked for Josanne to be put on emergency list but further attempt by Registrar to insert cannula for IV access was successful at 15.00hrs. That evening Deprivation of Liberty Safeguard (DoLS) application completed at 18.02 hrs, triggered by need to use mittens to restrict ability to pull out cannula etc. and submitted to Adult Safeguarding Nurse. Upon receipt of DoLS application that evening Adult Safeguarding Nurse informed the Health Liaison Team (HLT) Learning Disability Liaison nurses¹⁴. No Learning Disability alert on the hospital system as Josanne was not on the Hertfordshire County Council Learning Disability register.

Josanne had in excess of 10 seizures. St E's care staff raised concerns with ward staff but felt they were not listened to. Care staff contacted Nurse at St. E's to escalate concerns. Nurse from St E's called the ward to discuss the St E's carers concerns. St E's documented that the Nurse on the ward said they (hospital staff)

¹⁴ Learning Disability Liaison Nurse is a specialist nurse who supports people with a learning disability while they're in hospital to make sure they get the care they need, <https://www.nhs.uk/conditions/learning-disabilities/going-into-hospital/>

were doing all that was expected of them and that she was unhappy that St E's had brought these concerns to her attention. It is documented that St E's nurse reminded ward nurse about the importance of implementing seizure management guidelines.

23.40 hrs Josanne is significantly unwell; raised respirations and reduced oxygen saturation, she is unresponsive and hypotensive, tachycardic, and having frequent seizures, 13 since 15.15hrs. She is assessed as having developed aspiration pneumonia likely secondary to seizures. 01.23 hrs seen by Registrar, who requested ITU medical support, ITU consultant attended. Doctor contacts Mother and explains Josanne is very unwell and likely to pass away. Discussed Do not attempt Cardiac Pulmonary Resuscitation (DNACPR), Mother agreed but it is noted that they were not happy with decision. Josanne was given antibiotics and IV fluids. Critical care outreach team supporting Josanne on ward. On call physiotherapist called in to give chest physio and suction secretions - trying to clear chest. Seizures continue. Overnight medical team notes Josanne was not receiving all anti-epileptic medication due to not having PEG in place.

- 7.45 **25th January 2017** Further to contact from Safeguarding Team at Lister Hospital to inform the Health Liaison Team (HLT) of Josanne's admission and DoLS application the HLT arranged to assess Josanne on 26/01/17. A colleague from another community service who had visited St E's also made HLT aware of concerns that St E's carers had raised with them about Josanne's care in hospital. Specifically, that they felt not listened to by ward staff and were concerned about seizure control and lack of nutrition and hydration. HLT contacted the Safeguarding Team at Lister hospital, to advise of concerns and to request a visit to the ward to assess the situation and feedback to HLT. E-mail also sent to Lead Nurse Adult Safeguarding at Lister Hospital to advise that seizure activity is reported to have increased, concern that carers are not being listened to, concern around medication and nutrition as RIG not in place and concern that surgery to replace RIG has been postponed.

Josanne reviewed by a Consultant. Josanne being treated for right sided pneumonia, probable right sided collapse (lung) and possible pulmonary embolism¹⁵, too unwell for diagnostic test. IV fluids and antibiotics continued and treatment for potential blood clot started. Neurology referral sent for optimisation of anti-epileptic medications.

Josanne seen by a Consultant neurologist, who noted prescribed anti-epileptic medications and acute care plan for use of Buccal midazolam and Paraldehyde (not usually stocked in hospital). Consultant contacted St E's Specialist Epilepsy nurse to discuss medication etc. Blood tests requested to check levels of specific medication to ascertain if getting therapeutic dosage, increased the dose of another anti-epileptic medication and requested that pharmacy obtain Paraldehyde if possible, also requested from St E's, which was taken in to hospital. Naso Gastric Tube recommended for regular medications. IV access maintained.

¹⁵ Pulmonary Embolism happens when a blood vessel in your lungs becomes blocked. Most of the time, this blockage is caused by a blood clot, <https://www.blf.org.uk/support-for-you/pulmonary-embolism/causes>

Josanne seen again later in evening by Consultant Neurologist, advised on phenytoin dosage and rectal diazepam. Ward manager was contacted by St E's manager raising concerns that the seizure termination plan was not being followed. Seizure termination plan was found in back of medical notes-Medical team not aware of this document. Ward manager got the medications prescribed and ordered from pharmacy.

7.46 **26th January 2017** Josanne continued to have seizures, and present with symptoms of rapidly deteriorating condition including low blood pressure, high temperature, not passing urine, collapsed veins. 02.45 hrs Anaesthetic Registrar inserts a central line (Central venous catheter)¹⁶. Continuous input from CCOT and Consultant medical teams.

10.15 hrs Josanne suffers a cardiac arrest and sadly death was confirmed at 10.47 hrs.

7.47 Throughout Josanne's admission from **11th January 2017** St E's staff raised concerns with ward staff and with nurses and managers at St E's, whom also contacted the ward. The concerns were about her distress, lack of nutrition and hydration, general care and support and questioning when the procedure for PEG re-siting was scheduled. Along with this, concerns about the significant risk of seizures (pointing out that Josanne had been seizure free since 2014) if the prescribed medication was not administered directly via a PEG tube. St E's staff report that they felt they were not listened to, their concerns dismissed and unsupported by ward staff.

¹⁶Central venous catheter, also known as a central line, central venous line, or central venous access catheter, is a catheter placed into a large vein. Catheters can be placed in veins in the neck, chest, groin, or through veins in the arms. It is used to administer medication or fluids that are unable to be taken by mouth or would harm a smaller peripheral vein, https://en.wikipedia.org/wiki/Central_venous_catheter

8. Findings and Analysis of Themes

8.1 The table below details the findings and themes in terms of what happened/didn't happen/gaps, opportunities and good practice under each of the three key episodes.

| Key episode 1: April-August 2016 | | |
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| What happened/didn't happen and Gaps | Missed Opportunities | Good practice |
| <ul style="list-style-type: none"> Multiple referrals and no clear communication or plan led to time delay No Multi Disciplinary Team (MDT) meeting called to bring all involved together to consider issues/needs and agree plan Joint person centred working to look at creative thinking on how to manage the feeding tube to prevent it being pulled out Reasonable adjustments not considered in terms of fast track referral | <ul style="list-style-type: none"> Roles and responsibilities Pharmacy-potential for more proactive-involvement/intervention. Appreciation of roles, responsibilities Tissue viability referral Review referral process when needing a review/opinion from another speciality to reduce steps and delay Information sharing about Learning Disability and optimising involvement of Liaison Role | <ul style="list-style-type: none"> Referrals followed up-person centred working Joint working with Dietician and Abbotts nurse |
| Key episode 2: September-December 2016 | | |
| What happened/didn't happen and Gaps | Missed Opportunities | Good practice |
| <ul style="list-style-type: none"> Excessive length of time for appointments following referral Lack of Communication no 'handover' from PAH to E&NHT Mental Capacity Act (MCA) and Deprivation of Liberty Safeguards (DoLS)- MCA and Best Interests not applied in relation to Josanne's capacity to consent to being in hospital. No clear lead/action to consider proactive management of Josanne pulling out tube. | <ul style="list-style-type: none"> No MDT and Co-ordination to ensure clarity for all in terms of intervention/objective-who, when, what Advocacy to ensure Josanne's voice is heard Sustainability and Transformation Programme to look at processes for residents of Herts & Essex around care pathways & referral e.g. Herts residents using PAH | <ul style="list-style-type: none"> St E's advocating on J's behalf; their refusal for J to return home without a plan and following up referrals/appointments, St E's staff always with Josanne when in hospital-person centred care Hospital passport/purple folder-containing important information about Josanne |

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| <ul style="list-style-type: none"> • No system/process to connect or Flag that various professionals/departments are involved • Learning Disability flag for care planning and consideration of reasonable adjustments in place at PAH but this did not transfer to E&NHT • Lack of communication/co-ordination between hospital, community, GP and St E's in relation to care and intervention and decision to refer to E&NHT • Discharge-medically optimised, different definitions of safe and adequate • No MDT meeting following surgical review resulted in poor communication and the Responsible Consultant at PAH making a referral to ULCH whilst possibly not aware that a referral had been made to E&NHT | <ul style="list-style-type: none"> • Multiple attendances/admissions should have triggered a review with the 'frequent attenders' system/process • Hospital passport/purple folder and St E's staff knowledge of Josanne could/should have been used effectively • Summary of care record/notes should be completed by GP to identify needs including communication and any reasonable adjustments • Missed opportunity for escalation of concerns at an earlier stage | |
| Key episode 3: January 2017 | | |
| What happened/didn't happen and Gaps | Missed Opportunities | Good practice |
| <ul style="list-style-type: none"> • Understanding and appreciation of roles and responsibilities and communication between hospital and St E's and Consultant to Consultant • Epilepsy medication and seizure management plan- the existing epilepsy management plan was not used. Alternative solutions and additional expertise re medication was not sought until late in admission • Information sharing- information about Josanne's past history of procedures at PAH was not available to E&NHT and detail within Purple folder was not used | <ul style="list-style-type: none"> • Application of a protocol re bringing medication from home and joint discussion about reasonable adjustments/ exploration of alternative administration routes should have happened • Early involvement of pharmacy and specialists e.g. Neurologist to ensure critical anti-epileptic medications maintained • System and process for allocation for surgery and decision making criteria to remove patient booked onto | <ul style="list-style-type: none"> • Compassionate and caring, St E's staff with Josanne throughout admission and evidence that raised concerns with ward staff • Person centred and courageous, Dietician highlighted concerns and submitted Datix incident report • Ward Sister raised concerns |

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| <ul style="list-style-type: none"> • Record keeping, charts and monitoring not always completed and/or acted upon • Person centred care- Josanne was not seen as a 'whole' person which meant that some of her most basic needs weren't met. There seemed to be a lack of compassionate care and consideration of how Josanne might be feeling- 'stepping into the shoes' of Josanne • St E's staff knowledge of Josanne was not listened to or sought • A lack of 'curiosity' about how best to keep Josanne safe well, and seizure free whilst no PEG in was place, and only some medications available/taken • No ONE person taking lead for Josanne's care and treatment on the ward. Josanne not on a Gastro ward • Gap around referral/early intervention from Physiotherapy around postural awareness and aspiration pneumonia • MCA Best Interests not communicated effectively and initiated early enough. there was no consideration of 'possey mittens', or timely escalation to theatre for central line when IV pulled out • Lack of Joint working to undertake risk assessment of needs and confirm what actions were to be taken; who was co-ordinating care and by when. • Failure to recognise a deteriorating patient • Delay in escalation when the procedure was repeatedly postponed , and Josanne's condition caused increasing | <p>emergency list needs to be robust and understood</p> <ul style="list-style-type: none"> • System and process to ensure safe and effective care if patient is an 'outlier'- PEG/feeding tube pathway • Josanne's name/experience is used frequently in E&NH Hospital to prevent happening again- is this an opportunity for wider system learning? • Multiple/frequent admissions/attendances particularly with the same presenting need/symptom at any hospital within a short number of months should trigger MDT on admission? • Purple folders (about me information)- opportunity for joint working to review what is in the folder now, what needs to be in particularly focused on the 'Grab sheet', gain ownership and increase value of folder. Joint training with hospital staff and providers/family carers to promote equal responsibility to ask for and to provide the folder | |
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|---|--|--|
| <p>concern as she deteriorated within E&NHT</p> <ul style="list-style-type: none">• System trigger for 'frequent attenders' if this was in place it may have triggered a MDT review.• Person centred Planning, joint working-Lack of proactive discussion with St E's specialist nurses and the involvement of Neurologist and Pharmacist in relation to prescribed medication and availability in hospital• Notes and purple folder- Josanne's Epilepsy management plan was lost amongst other documents• Learning Disability Liaison nurses were not made aware of Josanne's admission by hospital staff, query awareness of St E's of liaison nurses• ENHHT Trust policy for the care of people with a learning disability was not followed, e.g. no Learning Disability flag in place or applied | | |
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8.2 The analysis and learning from the findings detailed in the table above have been grouped into four themes:

- Communication and co-ordination
- Person centred care, approaches and planning
- Systems and processes
- Ways of working

8.3 Communication and co-ordination

Josanne had input from and contact with a number of different agencies and professionals to support her wellbeing and to stay healthy- physically, psychologically and emotionally, living a good quality life. St E's staff knew Josanne well and had worked with her family and others in her life to develop a person-centred plan which provided the detail about the things that were important to and important for Josanne. Along with her person-centred plan Josanne also had care plans and her about me 'My Purple folder' which gave lots of important information about her health and needs. Despite all of these things the chronology, IMRs, learning event and hospital Serious Incident (SI) review identified a lack of clear communication, with some examples of 'silo' working, and no clear co-ordination of actions and referrals in response to changes in care needs. There was evidence of responsive and timely review, intervention and referrals made within the community, for example the communication St E's initiated with the GP, Community Dietician and Abbotts nurse and the joint working approach implemented between the Community Dietician and Abbotts Nurse. Consistency of communication and co-ordination was ineffective during what became Josanne's final admission to hospital.

Following referral by the GP in May to PAH Consultant Gastroenterologist for review and possible re-siting of PEG, subsequent appointment with Endoscopy resulted in a request for and referral to Surgical Consultant for assessment of the granuloma. The outcome of which was discharge back to Endoscopy at PAH. Communication then becomes less clear. There appears to have been a lack of communication/co-ordination between hospital, community, GP and St E's in relation to care and intervention and the decision to refer to E&NHT Lister Hospital which resulted in no communication or handover taking place; the referral from the GP to E&NHT Lister Hospital sent on 30th November 2016 requesting an appointment for a 'tube change' in February 2017, this was received subsequent to emergency admission. There was no Multi-Disciplinary Team (MDT) meeting following the surgical review and discharge back to Endoscopy; the impact of which was a lack of co-ordination and poor communication in relation to planned next steps. The Consultant Surgeon at PAH made a referral to University College London Hospital (UCLH) in December 2016, E&NHT were not aware of this referral and it is not clear who was aware and if the Consultant at PAH was aware of the GP referral to the Specialist PEG Nurse at E&NHT.

During these months Josanne had received treatment for infection in and around the PEG site and had started to pull out the PEG. Co-ordination of a Multi-Disciplinary Team meeting within the community would have been beneficial to consider Josanne needs, the presenting issues, explore actions and agree a plan together. The plan could have included creative thinking about how best to proactively manage Josanne's interest with her tube whilst referrals were progressing. At the learning event suggestions were made that a 'placebo' tube could have been placed so that Josanne pulled this and not the actual tube and/or the use of 'possey mittens' to restrict ability to grip tube. This MDT approach would also have confirmed responsibilities, timescales and clarity for everyone involved, highlighting the actions being taken and by whom.

St E's ensured communication with the GP and other professionals, which continued with care staff from St E's acting as advocate for Josanne when admitted to hospital. It is clear from the analysis and learning that during Josanne's final admission communication with the ward staff was compromised. St E's staff described ward staff having a dismissive response, not listening and a lack of openness to the valuable information that St E's staff had. There was a missed opportunity to use the information available including critical information about seizure management contained within the 'Purple folder'. The information contained in the Purple folder should support medical, nursing and other clinical staff to quickly gain the key information about a person with a learning disability who may not be able to communicate their needs. St E's staff are clear that the folder was taken to the hospital and given to E&NH staff but there was no acknowledgement of receipt of the folder and a resulting disconnect in communication. From the learning event it was clear that the information contained in the folder needs to be reviewed to ensure that only vital information is contained within the 'grab sheet' and is easily accessible and more importantly understood and valued by all hospital staff.

Delay in referrals and lack of communication and co-ordination throughout Josanne's final admission to hospital resulted in Josanne going for a significantly long period of time Nil By Mouth (NBM) which must have been very uncomfortable and distressing for her as well as placing her at risk of re-feeding syndrome, as identified by the dietician in her documented notes, and seizures due not receiving the critical medication. There seems to have been a lack of understanding and therefore timely action in respect of Josanne's lack of capacity to consent and the requirement to engage early with those who know her well, i.e. family and St E's staff.

No one person taking a co-ordinating role resulted in lack of a clear plan, timely referrals, follow up of actions along with significant gaps and delays in communication. The information returned as part of the SAR indicates confusion about who was booking a theatre slot for Josanne's procedure to be carried out, what the plan was for Josanne's on-going nutrition and hydration, the mechanism to ensure administration of critical medication and actions to prevent re-feeding syndrome. Holding a Multi-Disciplinary Team (MDT) meeting, involving medical, nursing and Allied Health Professionals, St Es' carers and Specialist Epilepsy nurses and family would have led to a clear holistic plan being in place with an

identified lead co-ordinating care with clear communication and clarity of roles and responsibilities for all involved.

Learning point 1 and 2

1. Where there are multiple agencies and professionals involved in the care and support of an individual with a learning disability and complex/multiple physical health care needs, it is critical to have a clear plan and effective mechanisms for communication and understanding of the individuals support needs and actions i.e. what, when and who is in place. Continuity of care when a person with a learning disability and complex/multiple health needs is admitted to hospital should always be paramount.
2. Clarity of communication and co-ordination reduces the risk of delays and gaps in care and promotes continuity and will in addition facilitate 'courage' to challenge gaps, delays and deviation from the plan by those involved in providing care.

Recommendation 1 Multi-disciplinary working, care planning and co-ordination

8.4 Person centred care, approaches and planning

Josanne's needs, hopes and wishes and how best to support her were well known and had been effective for several years, resulting in a good quality of life that was seizure free despite having severe epilepsy. Person centred care/approaches requires the person's holistic needs be put at the very centre of thinking to generate questions and discussion about how best to continue to meet a person's needs when change, risks or challenges happen. There was a missed opportunity for joint person-centred planning when the referral was made for review of the granuloma and possible re-siting of the tube, repeated infections and increased frequency of pulling out the tube. Multi-agency Person centred working would have helped everyone understand what was currently happening, considering what the impact on Josanne's wellbeing might be with the granuloma and pulling out the tube. This approach would generate discussions and different views and ideas, possibly leading to creative thinking on how to manage Josanne's interest in her tube and reduce or prevent it being pulled out, both as an interim plan whilst referrals progressed for possible re-siting of the tube and management of the granuloma.

During her last admission Josanne had long periods of time with no nutrition or hydration. What must this have felt like for her, feeling constantly hungry, thirsty and having a dry mouth? Despite St E's trying to advocate for Josanne, the learning shows that she was not seen as a 'whole' person which resulted in some of her most basic human needs not being met. There seemed to be a lack of compassionate care and consideration of how Josanne might be feeling. In addition there was a failure to challenge colleagues to do more, make decisions, and have a clear plan. Person centred care/approaches would have facilitated joint working with and timely proactive discussion between different clinical colleagues, St E's staff and Josanne's family. Person centred care/approaches would have triggered early involvement of the Consultant Neurologist and Pharmacist and engagement with the St E's Specialist Epilepsy nurses in relation to prescribed

medication availability in hospital, and possible alternatives given the challenges with the route of administration.

When someone has limited communication, those around that person need to learn to understand what the little gestures, body language and other non-verbal clues are and what the person wants to communicate. It is understood that when someone goes to hospital there is not always the time to get to know the person well, therefore those who know the person and hospital passports/about me folders such as the 'My Purple folder' are essential. In the IMR's and at the learning event it was very clear that St E's staff tried to advocate on Josanne's behalf; being clear about her needs in relation to administration of her medication, promotion of her basic needs and escalating their concerns to ward staff as Josanne deteriorated. Sadly, St E's staff were not listened to and, in one instance, told not to continue raising the issues. The extent of the failure of hospital staff at E &NH Trust to listen to St E's staff concerns raised as part of this SAR led directly to a new safeguarding enquiry being opened and to this extent a review of safeguarding threshold and process criteria is recommended.

Having access to information such as the 'My purple folder', along with staff who know the person well, should support holistic person-centred care. St E's staff stayed with Josanne around the clock when in hospital for her support and comfort and to support the ward staff. Other mechanisms for assessment, monitoring and planning such as regular physical checks, fluid and nutrition charts, weighing and arm circumference measurements, and administration of medication were put in place whilst Josanne was in hospital but were not always accurately recorded or reviewed and when Josanne was deteriorating, actions were not timely.

Learning point 3 and 4

3. Putting each individual and their needs at the centre of their care and decision making, promoting the opportunity to hear the persons voice even when they don't use words to communicate is essential for person centred holistic care. Having an 'about me/hospital book or 'My Purple folder' is an effective mechanism to help hospital staff to understand critical needs as well as how best to communicate with a person with a learning disability.
4. Implementing the LD flag. The process for 'flagging' that a person has a learning disability and may need additional support/reasonable adjustments needs to be explicit and 'everyone's' responsibility. Staff need ongoing learning disability awareness training to have confidence when supporting a person with a learning disability, promote person centred working, encourage curiosity to understand each individual's needs, appreciate and facilitate continuity of care, trigger the asking of questions to understand the severity of individual conditions along with any critical procedures/interventions, and to make 'reasonable adjustments' as required.

Recommendation 2 Hospital Passport/About me Purple folder

Recommendation 3 Learning Disability Flag, reasonable adjustments and continuity of person centred care

8.5 Systems and processes

Both PAH and E&NHT have a policy and process in place for flagging the needs of a person with a learning disability. This flag identifies that the person has a learning disability and may need 'reasonable adjustments' to be made and to trigger care planning. Josanne had been known to PAH since 2014 and an LD flag was in place there. Unfortunately, no flag was in place at E&NHT as she was not known to them, however admission notes indicate that staff were aware that Josanne had a learning disability, but the trust policy was not followed. As there was no flag on the system the Learning Disability Liaison nurse service were not automatically made aware of Josanne's admission. However, the policy in place at E&NH Trust supports staff in the hospital to make a referral to the liaison service for support for any patient they believe to have a learning disability irrespective of if an LD flag is on the system.

Josanne's 'Purple Folder' which contained vital information about her needs was taken to the hospital but from the information provided it appears that this information was not used. There seems to be a gap in awareness and understanding about the 'Purple folder' and how this is both valued and used, particularly the 'emergency grab sheet' contained within it. The SAR process and learning event also identified a gap in the established process of flagging and tracking of the needs of people with a learning disability. Currently Herts Local Authority have a process to verify details of people with a learning disability known to the Local Authority and registered with a GP. In line with best practice this information is shared with NHS Trusts and a 'flag' put on the Patient Administration System (PAS) to trigger the fact that the person may need 'reasonable adjustments' and alert to specific care plans etc. Josanne was placed at St E's in Hertfordshire and care funded by Cambridgeshire Local Authority and therefore despite being registered with a GP in Hertfordshire she was not known to Herts County Council and therefore her details had not been shared with the hospital for a flag to be added. Although there was no existing flag in place St E's staff were advocating Josanne's needs and had the 'Purple folder' with them for hospital staff. The flagging of a person with a learning disability is part of the hospital policy for supporting a person with a learning disability and supports staff within the hospital to make a referral for the Health Liaison Team for support. This is not reliant upon having an existing flag in place. As with any member of the public a person with a learning disability could potentially attend any hospital across the UK, therefore the hospital passport/about me folder known locally as the 'Purple folder' is essential to provide clinical staff with critical information about the person with a learning disability. The existing policy for flagging and meeting the needs of people with a learning disability when in hospital needs to be applied in practice, which didn't happen for Josanne.

Josanne's Epilepsy management protocol got 'lost' within other documentation and there was no referral/request for input from a Consultant Neurologist, Pharmacist or contact made or discussion with the specialist epilepsy nurses at St E's until the day before she died. Whilst Josanne was initially tolerating oral administration of the AEDs which were not able to be administered via IV from 17th January, 6 days into her stay Josanne started to refuse medication and by 18th

January she had missed 6 doses and no alternative plan was implemented. The Hospital Serious Incident (SI) and learning event identified the need for better understanding and then flexibility of the system to acknowledge and respond appropriately when medications are critical, taking into consideration the Mental Capacity Act for an individual who lacks capacity to consent and was refusing oral medications.

Josanne had numerous attendances and admissions between October 2016-January 2017 with the same presenting need/symptom i.e. pulling out of PEG. From the information provided and discussion at the learning event it appears that the focus was solely on re-insertion of the PEG or alternative tube with little if any consideration of the impact for Josanne's wellbeing of removing the tube frequently or consideration as to the cause for this. These repeat attendances should have triggered an MDT, which would have resulted in improved communication and understanding of actions and planning to better manage Josanne's increasing successful attempts to pull out her tube.

The complexity with referrals made within the hospital and lack of communication led to assumptions in responsibility and significant delays in care. The referral to the relevant consultant/department to progress with the PEG re-siting was delayed. The SI review undertaken by Lister Hospital identified the need for a clear referral pathway for PEG and review of the Standard Operating Procedure. At the time of writing the SAR overview report this has been completed and subsequently audited.

Scheduling for theatre list and the process in place for management of 'emergency' cases appears to have been inconsistent and mis-communicated. The result of which was Josanne being kept NBM for over 6 days and at no point during her admission having the procedure completed. Following escalation of concerns by the ward Sister about the delay in Josanne going to theatre for the procedure, a slot was booked on the emergency theatre list on 20th January 2017 and Josanne was prepped for theatre however this did not take place as a 'more urgent' case took the slot. It should be noted that this cancellation was on a Friday and there was no plan to schedule for emergency over the weekend. Again, this was an action area from the SI undertaken by the Lister hospital resulting in implementation of planned theatre time, with flexibility for the theatre team to support in endoscopy suite as required.

There was a failure to recognise, respond to and escalate Josanne's deteriorating condition. Josanne's poor diet and fluid intake, declining to take oral medication, intermittent IV access impacted on her physiological presentation and should have been responded to in a timely manner. E&NH Trust has a policy in place for staff to follow in relation to the monitoring and escalation of physiological observations, on which staff receive training, unfortunately escalation didn't happen until very late at which point Josanne was significantly unwell.

IV access was essential, both for some of Josanne's medication and fluid intake, yet despite knowledge that it was difficult to gain IV access and that when inserted

Josanne would frequently dislodge the cannula for IV access there was significant delay in establishing definitive IV access.

On her final admission to hospital there was a failure to effectively utilise the Mental Capacity Act and Best Interest Decision making processes (assessment and best interest decision making, consideration of and actions to ensure best interests and timely intervention, ensuring that those who knew Josanne well were involved). There was no consideration of whether Josanne could consent to being on the ward so no documented MCA/BI on this area and therefore no DoLS application until much later. The DoLS process would have included a Best Interests discussion and may have highlighted Josanne's additional needs due to her learning disability and initiated involvement from the Learning Disability Liaison team at an earlier stage as well as alerting the Safeguarding team at the hospital of her admission and additional needs as it did later on. DoLS is about consent to remain on the ward using the Cheshire West 'acid test':

Over 18:

- Under continuous supervision and control
- Not free to leave

and

- Lacks capacity to consent to these arrangements

Being in hospital and the ward environment would be considered 'continuous supervision and control' and should have triggered an application and referral to safeguarding

This led to delays and a seriously compromised deteriorating situation for Josanne. The plan on admission seemed clear but the relevant referral and booking of the theatre slot, along with early discussion with those who know Josanne well, in terms of best interest decision making as she lacked capacity, was delayed. Despite Josanne lacking capacity and refusing her critical medication there was a failure to consider an alternative plan. There appeared to be poor understanding of the requirements of the Mental Capacity Act and hospital procedure/process for consent when following best interests, which again delayed progress. The hospital SI identified this as an action and staff have received training along with practical learning with the introduction of real case studies.

There was no escalation to the adult safeguarding team despite increasing concerns. The adult safeguarding team only became aware of Josanne's admission on 24th January, when a DoLS application was sent through to them relating to 'use of mittens to restrict ability to pull out cannula for IV therapy/intervention'. Despite escalation of concerns at ward and department level.

There was a datix incident report submitted by the HCT dietetics team raising concerns about poor care on 23rd January, this was not raised as a safeguarding concern.

Learning point 5, 6 and 7

5. Multiple attendances/admissions should have triggered a multi-disciplinary meeting/review.
6. The Mental Capacity Act provides a legal framework to assess capacity and use 'best interest' decision making, involving those who know the person well when they are identified as lacking capacity. Deprivation of Liberty Safeguards ensures consideration of consent in all aspects of care and treatment.
7. Awareness of the 6 Safeguarding adult principles, individual responsibilities within the care act as well as good understanding of the management of process to report and respond to concerns/complaints including escalation.
 - A clear pathway for PEG procedures which describes actions by whom, when etc. along with clarity as to who assumes the co-ordinating role, facilitates MDT discussions and senior decision making when a person with a learning disability with complex/multiple needs is admitted to hospital reduces risks of delay and gaps in care.
 - Robust and well understood processes for inter-disciplinary and inter-departmental working facilitates, recognition of and timely action for the deteriorating patient and mechanisms for escalation.

Recommendation 4 Mental Capacity Act and Deprivation of Liberty

Recommendation 5 Patient journey and recognising a deteriorating patient

Recommendation 6 Local system for repeat / frequent attendances

Recommendation 7 Safeguarding Adult Principles and Process, reporting and responding to concerns/complaints

8.6 Ways of working

From the information provided and the learning event it is clear that there was a lack of understanding and appreciation for the different roles and responsibilities of all those involved in Josanne's care. Importantly, a collective view from the learning event was that there was no co-ordination or clarity of who was doing what, working to one plan both in the community and crucially on admission to hospital. This led to assumptions being made, delays and failures in both individual and collective actions. In the hospital setting no one person seemed to take responsibility for progressing with the documented plan for Josanne. The critical information held in Josanne's purple folder and held by St E's staff and her family were not appropriately sought and, in some incidences, actively not listened to when offered or escalated.

It is difficult to understand how decisions around prioritisation of needs were made, particularly considering the Trusts duty to make 'reasonable adjustments' to process and procedure as required due to Josanne's learning disability. Josanne came into hospital healthy but requiring what should have been a routine procedure to replace the PEG tube, which has been detailed as essential to Josanne's continued wellbeing particularly in relation to management of her epilepsy. At no point was a multi-disciplinary person-centred planning meeting

initiated including family and St E's to consider contingency and alternative interventions when there were delays in progressing with the PEG procedure.

The 'clunky' and time-consuming system that was in place for referrals to different departments and booking of theatre time had the provision for 'emergencies' and yet, despite being on the emergency list several times, the procedure never happened for Josanne. The learning from the hospital SI has now seen a PEG pathway developed and implemented as well as changes to the process for 'emergencies'.

There is also an opportunity for an individual to have in place tracking and monitoring of actions agreed, irrespective of who initiates the action, through clear, agreed joint multi-disciplinary working resulting in one care plan.

There is compelling evidence from the learning for increased awareness of and ownership for joint and multi-disciplinary working. Roles and responsibilities of all those involved in one person's care needs to be clear so that the agreed plan, including contingency, escalation and responsibility of co-ordination are well understood and care is seamless, effective and of consistent high quality. Confidence to trigger a multi-disciplinary meeting as a mechanism for holistic management of care whether in the community and when admitted to hospital is incumbent on each individual who has input into an individual's care.

When admitted to hospital, staff from St E's who had supported Josanne on a daily basis over many years should have found that their views and knowledge of Josanne and her needs were valued and respected. The reality was that the culture within the hospital and hierarchy failed to promote a collaborative joint working approach which led to a non-listening environment. Advocating for someone who is unable to speak up for themselves, utilising and seeking all available information about the person and their needs and wishes requires effective communication with respectful challenge. The learning identified a lack of joint working, effective communication including information sharing which led to gaps in care and resulted in Josanne's avoidable death. Learning also identified the need for better shared understanding of escalation of complaints and concerns as well as safeguarding procedures and responsibility to raise concerns.

Learning point 8

8. Promotion of safe, high quality and effective care is the business of every staff member irrespective of where they work. Training/awareness, policies and procedures are only effective if put into practice. Using Josanne's experience to 'step into the shoes' of each patient, provides a collective opportunity to 'test' the person-centred approach, think holistically about each patients' needs, facilitate and value understanding of a person with a learning disability from those who know them well; listening and hearing what is shared.

Recommendation 8 Person Centred Planning

9. Conclusions

The review has looked at the very sad and distressing, premature and avoidable death of Josanne. Josanne's family have been very clear that their hope is that this review will help agencies and individuals to learn, improve and make a difference for people with a learning disability and their families in the future.

E &NH Trust undertook a Serious Incident investigation which led to the drafting of a detailed action plan. Actions including review of processes for referral, PEG pathway, recognising the deteriorating patient, training to improve understanding of MCA.

One question that was considered as part of the learning event and arose due to the analysis and learning from the chronology, IMR's and SI was in relation to equal treatment. As a SAR panel and wider stakeholders, the question was asked 'would the experience be the same for someone without a learning disability'? The analysis and learning has identified things that didn't happen that should have, there were missed opportunities and some good practice; considering all of the findings and learning identified it is the view of the report writer and chair that Josanne did not receive equal treatment, and during the last 16 days of her life, she wasn't afforded the support, care or compassion for the very basics of human need. The Mencap report 'Death by Indifference' 2007 and then the subsequent report '74 Deaths and counting' 2012 also from Mencap described the premature deaths of people with a learning disability where basic care, poor communication, late diagnosis or intervention, and not seeing the person were common features of their experiences which contributed to their death.

On reflection of these reports the chair is reminded of Lord Taylor's comments after the Hillsborough disaster highlighted that 8 previous inquiry reports had went unheeded. He made an emphatic point;

*"That it was allowed to happen, despite all the accumulated wisdom of so many previous reports and guidelines must indicate that the lessons of past disasters and the recommendations following them had not been taken sufficiently to heart...there is no point in holding inquiries or publishing guidance unless the recommendations are followed diligently. **That must be the first lesson**"*

Learning and good practice is only effective if implemented, it is hoped that the recommendations resulting from this SAR will achieve the learning and improvements that can make the difference for other people with a learning disability that Josanne's family would like to see.

10. Recommendations

1. **Multi-disciplinary working, care planning and co-ordination**

It is recommended that joint work is undertaken between community: primary and third sector and hospital staff to review and develop mechanisms for communication and person-centred care planning and evaluate to ensure the following outcomes:

- All involved are clear about their own and others' roles and responsibilities
- The care plans make explicit who is responsible for the various elements of the care plan in community and hospital
- All involved are clear of what circumstances should trigger calling an MDT and their accountability for this
- That for individuals with complex needs, the plan is both proactive and reactive and includes contingency plans
- That a coordinator is clearly identified

This work should be completed along with recommendations 2 and 8. There needs to be clear ownership and governance agreed for each agency/stakeholder to ensure actions agreed/developed are embedded into practice.

2. **Hospital Passport/about me- 'My Purple folder'**

The detail contained within the 'My Purple folder' and the 'grab sheet' needs to be urgently and jointly (i.e. hospital, St E's and community staff) reviewed. It is recommended that clinical (Medics, Nurses and Allied Health Professionals) representatives work together to ensure that the most relevant information to inform/support clinical decision making and intervention when attendance/admission to hospital or appointment with GP or other community professional is included within the grab sheet. This should then be considered with the whole folder.

For example, seizure management/rescue protocol for a person with epilepsy. In Josanne's situation the fact that she was reliant on the PEG for administration of medications should be part of the grab sheet.

Working together will facilitate shared ownership of the folder as learning from the SAR indicated poor perception and understanding of the importance of the information contained within. It would be helpful to use the learning from this SAR and Josanne's experience as a framework to think through what needs to be included so that the 'why', the 'what' and 'how' is embedded into practice.

3. **Learning Disability Flag, reasonable adjustments and continuity of person-centred care**

How the LD flag is utilised as part of the agreed policy to support fair and equal treatment for people with a learning disability when attending or admitted to hospital should be reviewed with representatives from both frontline and senior

hospital staff, the Learning Disability Liaison team, Local Authority, and community staff i.e. a representative from General Practice.

As part of this review consideration needs to be given to when a patient attends and/or is admitted from 'out of area' and staff understanding of the policy so that there is not a reliance on there being an LD flag to initiate the involvement of the Learning Disability Liaison Team and highlight potential reasonable adjustments needed.

The current Learning Disability awareness training which has already been reviewed by E&NH Trust following the SI needs to be considered jointly and thought given to the value of joint training with community colleagues.

4. Mental Capacity Act and Deprivation of Liberty

Understanding and implementation of the Mental Capacity Act (MCA) and the hospital policy has been reviewed as a result of the SI.

Joint understanding of the principles of MCA, acting in the Best Interests of an individual and the use of DoLS both in the community and hospital should be revisited to check consistency of application. Specifically, it is recommended that each agency comes together periodically, i.e. annually to jointly review findings from the MCA audit (which if not already completed needs to be completed by each agency) to:

- Jointly identify gaps and opportunities
- Agree actions as part of learning and training.
- HSAB has developed an MCA App, it is recommended that mechanisms for use of the App both in hospital and the community are considered.

Compliance with and implementation of the MCA and DoLS is monitored by providers, regulators and commissioners. It is recommended that HSAB as part of frontline visits should include observation of how the MCA, DoLS and safeguarding adult principles are embedded within practice.

5. Patient journey and recognising a deteriorating patient

Further to the SI and learning E&NH Trust have developed a PEG pathway which now has planned theatre time and agreed steps for senior decision making and reviewed processes for inter-disciplinary and inter-departmental working. This has made improvements to the process for referral as well as providing training to increase understanding/recognition of the deteriorating patient and implementation of the procedure for escalation.

It is recommended that this pathway is reviewed annually, and consideration given to this being undertaken as a peer review.

The SAR panel note that there is currently a national piece of work underway with SEPSIS¹⁷ leads reviewing 'recognising the deteriorating patient who has a learning disability' and it is recommended that the commissioning authorities i.e. CCG and Local Authority seek assurance when published that this guidance is rolled out and implemented within all agencies and that the HSAB via the relevant safeguarding leads is provided with assurance.

6. Local system for repeat attendances

All stakeholders to undertake a quality assurance exercise relating to the local system for identifying repeat attendances to health settings. The assurance criteria should include:

- that repeat attendances trigger an appropriate response that is proportionate to the presenting circumstances of the person and having taken account of relevant guidance
- that the response has considered equality and diversity including whether any 'reasonable adjustments' were made for people with a learning disability
- that for individuals with a learning disability and complex/multiple needs, their frequent attendance triggered timely community-based interventions and early review via a multi-disciplinary team as appropriate
- that all involved in that person's care plan were aware of their responsibility to trigger an early review via the multi-disciplinary team

7. Safeguarding Adult Principles and Process, reporting and responding to concerns/complaints

It is recommended that the Learning and Development sub-group of the HSAB review current joint training available to consider opportunities across health both in the community and within hospital and social and independent care to:

- increase awareness of the 6 Safeguarding adult principles,
- clarify individual responsibilities within the Care Act
- understanding of the management of process to report and respond to concerns/complaints including escalation.

As part of this review consideration needs to be given to individual roles and responsibilities of paid carers when supporting a person in hospital, seeking to see evidence of processes for clarifying roles to maximise person centred care through agreed expectations.

HSAB to seek assurance that the threshold and process for safeguarding adult referrals has been reviewed to ensure that statutory duties are actioned.

8. Person centred planning

It is recommended that there is joint working between E&NH Trust, PAH, St E's, Community Learning Disability colleagues and the Learning Disability Liaison

¹⁷ SEPSIS is a life threatening condition that arises when the body's response to infection causes injury to its own tissues and organs.

Nurse service to develop a framework to test holistic care for people with learning disability coming into hospital, to be known as the '**J test**'.

The '**J test**' should have a set of person-centred questions which require joint working with carers, whether family and/or paid, along with hospital staff to facilitate 'stepping into the shoes' of their patient with a learning disability and consider; 'What is the critical actions for this person?' 'Would this work for J?' 'What must this intervention/treatment/experience be like for ...?'

It is suggested that further to joint working for recommendations 1,2, 3 and 6 collective assurance is sought that this pathway and actions are continuing to be effective.

It is recommended that this report and recommendations therein are formally shared by the HSAB with CQC, NHS England/NHS Improvement and Universities to allow wider learning across health and social care and provide areas for consideration as part of ongoing monitoring. It is further recommended that during 2019/20 the HSAB undertakes a series of frontline visits to 'walk' the PEG pathway and ensure itself that recommendations have been followed through.

11. About the Independent Chair and Independent Author

Independent chair

Steve Holton is an Area Commander in Hertfordshire Fire and Rescue Service. He has over 26 years' experience working in the Public sector. He is a member of the Hertfordshire Safeguarding Adults Board and was asked to act as Independent chair due to his experience and neutrality. Steve has worked with CCGs, NHS trusts and the STP giving him a sound understanding of the Health sector.

Independent author

Judi Thorley was commissioned to work with the SAR panel to undertake the review and act as independent author. Judi is both a Registered Learning Disability and Registered General Adult Nurse with over 33 years' experience working within the NHS. Judi has worked in a range of services in leadership and clinician roles within Learning Disability, Acute services, Education and commissioning. Judi's previous roles include strategic regional Lead for learning disability health and safeguarding adults and from 2013 until 2018 Chief Nurse and Director of Quality and Safeguarding within 2 Clinical Commissioning Groups.

Since 2018 Judi has continued in a part-time role within the NHS and has carried out a range of independent consultancy work encompassing service review, review of arrangements for adult safeguarding, SARs and development and delivery of leadership development programmes.