

Camden Safeguarding Adults Partnership Board

“Safeguarding is everybody’s business”

A Safeguarding Adults Review Overview Report concerning “Mr V”

The name of the adult concerned has been anonymised to protect confidentiality

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Report published on 28th August 2020



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Executive summary

This Safeguarding Adults Review (SAR) was initiated by Camden Safeguarding Adults Partnership Board in 2019 following a recommendation from the local Learning Disability Mortality Review (LeDeR). This SAR considers the care and support received by Mr V from July 2013, when he was first reported as becoming unwell, leading up to his death in August 2017.

Mr V was a 57-year-old white man of Jewish heritage who was a resident in the London Borough of Camden. Mr V had severe and profound learning disability, he was partially sighted with hearing and mobility impairment. Mr V was unable to meet most of his activities of daily living and he was reliant on carers to maintain all his physical and psychosocial needs. Mr V was cared for in a supported living accommodation that had 24-hour care staff support.

Mr V had suffered weight loss and diarrhoea and was referred by his GP to specialist cancer service for suspected cancer of the colon in January 2014 and was placed on the two-week cancer investigation pathway in line with National Institute for Clinical Excellence (NICE 2005) guidelines¹.

Despite initial referral to hospital for suspected cancer of the colon due to a series of events Mr V did not receive the follow up and after care that he should have had.

As a result, there were missed opportunities for further investigations and identification of metastasis of the cancer to Mr V's lungs.

This SAR came about because of a Learning Disability Mortality Review (LeDeR) that was conducted for Mr V after his death.

The review highlighted good practice and quality end of life care, with all involved agencies working together to ensure Mr V was as comfortable as possible at the end of his life. The review also looked back to the initial cause of Mr V's illness and scrutinised the information presented from care notes, reports and hospital records. This review exposed issues around missed appointments, poor use of the Mental Capacity Act 2005 (MCA) and confusion around follow up medical appointments.

This SAR used the significant events methodology to examine the LeDeR timeline from when Mr V was first identified as being unwell up until his death.

All agencies and practitioners that were involved in Mr V's care and support took part in a learning event to reflect on what went well and what didn't go well in his care and treatment and to look at ways that can mitigate the same issues happening again.

¹ <https://www.nice.org.uk/Guidance/CG27>

The main issues that have been identified within this SAR are:

- The need for better advocacy for people who are totally reliant on others for all their care and support
- The use of the Mental Capacity Act 2005
- Ensuring that a named role/professional is responsible for the overall coordination of care for people with a learning disability who have complex health and social care needs
- Missed appointments for people who are totally reliant on others for all their care and support to be recorded as “Was Not Brought” as opposed to “Did Not Attend”

Recommendations

Recommendation 1: The Acute NHS Trust should monitor and ensure they are making IMCA referrals when someone is unable to consent to their treatment.

Recommendation 2: The Integrated Community Learning Disability Team should consider developing training and making the offer available to Learning Disability provider services regarding supporting a person with their health needs.

Recommendation 3: For all hospital passports/health care plans to be kept up to date and regularly reviewed. For people with severe and profound learning disability with complex health needs to have an up to date one page health profile to support GP and hospital appointments.

Recommendation 4: Develop a system that ensures a lead role/professional is agreed to coordinate care between the Acute NHS Trust and community services for a person with a learning disability.

Recommendation 5A: Health and social care providers should ensure that all clinical staff have access to support and advice on the MCA in addition to receiving training and written guidance.

Recommendation 5B: Health and social care providers should ensure that MCA policies are linked to relevant policies such as consent.

Recommendation 5C: Health and social care providers to ensure that the MCA profile is raised and continually refreshed.

Recommendation 5D: Health and social care providers, including CCG's, should ensure that the relevant organisational lead for MCA and DoLS is known throughout the organisation and that the person in this role should be available and able to provide expert guidance and support on any issues related to MCA and DoLS.

Recommendation 6A: Organisations who provide care for people with severe and profound learning disability with complex health needs should have clear accessible policies and procedures for staff to escalate concerns.

Recommendation 6B: Within staff supervision "Escalation of concerns" should be raised as a topic for discussion.

Recommendation 6C: The CSAPB to seek assurance that the Multi-Agency Escalation and Resolution Procedure is being utilised by partners.

Recommendation 7: Health and social care service providers must have a robust "Was Not Brought Policy" that is specifically targeted at adults who are unable to advocate for themselves and are totally reliant on others to support them to health appointments.

Acknowledgements

All agencies that were involved in Mr V's care have supported this review and their representatives made time to attend a significant event analysis meeting. At the meeting, they were fully engaged and involved in looking back at what went well in Mr V's care and what didn't go so well and being honest and transparent, as well as looking at ways that could prevent the same situation from happening again.

If Mr V's case had not gone through the LeDeR process, then the findings in this report may have been lost as to all intents and purposes. The review highlighted Mr V's end of life care was exceptional.

I am very grateful for the participation and support of all the agency representatives involved in the care of Mr V in the production of this report. It is very clear from speaking to those that knew Mr V well that he was a very special person with a big personality with people around him who genuinely cared for him and for his welfare.

Introduction

1.1. Circumstance leading to this review

The Learning Disability Mortality Review (LeDeR) Programme is a national programme aimed at making improvements to the lives of people with a learning disability by reviewing all reported deaths of a person with a learning disability from 4 years upwards.

Reviews of the deaths of people with a learning disability are usually carried out by trained reviewers who are working in health and social care settings and are based in the area where the person with a learning disability died.

In 2017 a notification of the death of a man with a learning disability was sent to the Camden Community Learning Disability service who then undertook the LeDeR review. The man (Mr V) lived in the London Borough of Camden and was 57 years old when he passed away.

The initial review revealed that Mr V was well supported at the end of his life and had good clinical input from community, acute Trust and social care agencies. However, on further scrutiny it was revealed that when Mr V had his initial diagnosis of cancer and had treatment at that time, failings were identified in the follow up for the treatment and after care. The Camden Safeguarding Adults Partnership Board (CSAPB) agreed the LeDeR review identified issues which met the criteria for a Safeguarding Adults Review (SAR) to be undertaken.

1.2. The statutory duty to conduct a safeguarding adult review (SAR)

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

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

Safeguarding Adults Reviews are required to reflect the six safeguarding adult's principles, as defined in the Care Act.

These are empowerment, prevention, proportionality, protection, partnership and accountability.

All members of the Safeguarding Adults Board must cooperate and contribute to the undertaking of the review so that any lessons learned maybe identified and this learning should be disseminated throughout all partner agencies.

A SAR is not about apportioning blame. Its purpose is to identify where there were issues in a person's care and to work together to resolve these issues and develop new strategies and learning that can be shared with all partner agencies. The reviews aims provide an opportunity for service improvement as Mr V's legacy.

1.3 Methodology and Terms of Reference

The SAR sub group of the CSAPB decided the most appropriate methodology to review Mr V's case would be that of a significant events analysis.

An initial meeting was held to discuss the terms of reference in December 2018, which involved the Camden CCG Designated Nurse for Safeguarding Adults, Head of Service for Camden Community Learning Disability Service, the Principal Social Worker from Camden Council and the independent author.

Themes agreed from the meeting:

The areas of focus for scrutiny and discussion were stated as

- ✓ Application of the Mental Capacity Act, Deprivation of Liberty Safeguards and best interest decision making.
- ✓ Communication: Information sharing, recording, discharge planning and management of appointments
- ✓ Advocacy: Roles and responsibilities, professional curiosity and escalation of concerns

It was decided that all agencies involved in Mr V's care since his initial diagnosis until the time of his death should be involved in the SAR.

The SAR is concerned with the time period from when initial concerns were raised about Mr V's health (July 2013) and subsequent referral to the cancer specialist service (January 2014) up to when his condition began to deteriorate (September 2016).

It was agreed by the SAR Subgroup of CSAPB, considering the circumstances, that the best methodology to use for this SAR would be a "Significant Events Analysis" underpinned by the initial LeDeR review and NHS Serious Incident (S.I.) investigation.

To facilitate this method all involved agencies were asked to attend a structured review for a full afternoon chaired by the SAR author, to scrutinise the timeline from the LeDeR review, identify any gaps in care and any opportunities for intervention that had been missed.

2: Review methodology

2.1 Significant Events Analysis (SEA)

Camden Safeguarding Adults Board has a set guidance (policy and procedure) that gives guidance on the process for undertaking a SAR and the criteria for acceptance of a referral.

Within the guidance there is a methodology decision tree which guides the SAB and its sub group members on which methodology is most suitable to use in each accepted referral.

In the case of Mr V the significant events analysis methodology was decided on as it was felt to be the best method of review for Mr V's case.

The significant events analysis has the objective for all the agencies involved in the persons care and support to come together to look at the issues and reflect on what happened and to work together to look at solutions and changes to practice.

The aim of this methodology is to understand what happened and why, to encourage reflection and identify what needs to change.

The key features of this methodology are

- It is group led (via panel), with a facilitator
- Staff/ adult/ family are involved via panel
- No chronology – although the LeDeR review provided this
- There are no single agency management reports
- There is one workshop: time saving cost effective

The advantages to this methodology are

- It has a “Light touch” and is cost effective
- It yields learning quickly
- There is full contribution of learning from staff involved in the case
- The ownership of learning is shared by all involved
- Supports a culture of openness and reflective learning
- It reduces the burden on individual agencies to produce management reports
- It may suit less complex or high-profile cases
- Trained reviewers not required
- The methodology is familiar to health colleagues

Some of the disadvantages are

- It is not designed to cope with complex cases
- The lack of independent review team may undermine transparency/ legitimacy however, in this case the chair and author was independent
- The speed of review may reduce opportunities for consideration
- It is not designed to include the family at the event

- Staff involvement may not suit cases where criminal proceedings are ongoing and staff are witnesses

There are 4 questions to ask when undertaking the significant events analysis

1. What happened?
2. Why did it happen?
3. What has been learned?
4. What has been changed or actioned?

All agencies involved in Mr V case showed they were committed to supporting the process of the SAR and were fully engaged in the significant events review event that was held on Tuesday 4th June 2019.

2.2 The agencies that were involved and contributed to this review

All the agencies that were involved in Mr V's care and support contributed to this review and demonstrated their commitment to learning and working together by attending the structured review event that was held on Tuesday 4th June 2019.

The following agencies were involved and represented at the structured review meeting

- Creative Support (The agency that provided 24-hour care and support to Mr V)
- London Borough of Camden Safeguarding Adults Team
- Camden Clinical Commissioning Group
- Royal Free London NHS Foundation Trust
- London Borough of Camden Commissioning
- London Borough of Camden Adult Social Care
- Mr V's GP from a Camden Practice
- Camden Community Team for People with a Learning Disability, including representatives from Social Work, Learning Disability Nursing and Speech and Language Therapy
- Central and North West London NHS Trust provider of District Nursing

3: Mr V a Pen Portrait

Mr V was a white male of Jewish heritage born in Israel in 1961 and moved to the UK five years later. He had family, mother and sister, that lived abroad but who maintained contact with him as regularly as possible.

Attempts have been made to contact the family to inform them of this review but so far there hasn't been any response.

Mr V was blind, hearing impaired and he had diplegic (meaning two limbs affected) cerebral palsy² which affected his movement and coordination, he had multiple physical disabilities as well as a profound Learning Disability.

Mr V was able to walk short distances with a walking frame and could move himself and navigate around his home quite well as it was a familiar environment, using a wheelchair if needed for longer distances and being pushed by a carer.

Mr V had some vocal communication and once people got to know him well they could understand the nuances of his communication. He was able to express when he was happy and when he was sad.

From a very young age, Mr V lived in the south-central region of England in a large institution built in the Victorian era for people with a learning disability. He lived there until he moved to a residential placement in the London Borough of Camden in 1993.

Mr V had good friends who he knew in the institution and who moved at the same time as himself to the same residential placement in Camden. Mr V had known his friends for many years and it seems fitting that he continued to share a house with them after his move from the institution.

Mr V received 24 hour care and support from care staff and he was reliant on care staff to meet all his health and social needs

Mr V had dysphagia, the medical term for problems with swallowing³, which usually manifested by coughing after he had been eating or drinking. He had problems with eating hard foods so he had a soft diet but only in more recent years. People who knew Mr V well reported that he was very sociable person and enjoyed taking part in local community based activities, listening to music, collecting soft toys, reflexology sessions once a week and engaging in art and craft sessions.

It was also reported that Mr V enjoyed foot spas which helped to calm him down if he was stressed and anxious. He benefited from use of sensory equipment that was set up in the sensory area of his home, this was another way he was able to relax. He also enjoyed going on holidays.

² <https://www.nhs.uk/conditions/cerebral-palsy/symptoms/>

³ <https://www.nhs.uk/conditions/swallowing-problems-dysphagia/>

It is reported that Mr V responded well to staff first thing in the morning and his communication passport was invaluable in supporting him in relaying to carers and others what support he needed.

People who knew Mr V well say that he had a very fulfilled life, he was a big personality and he was a well-liked person.

It was obvious from conducting this review and speaking to people who knew Mr V well that he was a very special and unique person with a lovely personality.

4: The structured review and key themes identified

4.1 Overview of the significant event review meeting

The health and social care services that were involved in Mr V's care were invited to the review meeting held at Camden Council offices for 13.00 to 16.30 on Tuesday 4th June 2019. All invitees were informed in advance by letter of the purpose of the event and guidance on the areas of focus for the review and provided with a copy of the LeDeR review. A chronology of contacts with services can be found in Appendix 1 of this review.

4.2 Identification of issues

Mr V had a profound learning disability and physical mobility problems and was referred to specialist cancer service for suspected cancer of the colon. Concerns about weight loss and diarrhoea were referred by the GP in January 2014 to hospital on the two-week cancer investigation pathway in line with National Institute for Clinical Excellence (NICE) guidelines⁴. Mr V was seen within the two-week NICE guidance with an outcome to have a lower and upper gastro-intestinal endoscopy, which is a camera inserted to see inside the body⁵. It was decided by the clinicians that the procedure should be carried out under sedation and, as the elective waiting list did not have space until May, the consultant requested he be put on an emergency list for the procedure.

Applying the Mental Capacity Act 2005

Mr V was assessed as lacking capacity to consent to the procedure and the sedation, therefore, under the Mental Capacity Act 2005⁶, it was noted he required a best interest decision, involving his next of kin, to proceed. However, there was difficulty in contacting the patient's family, who were out of the country, to discuss the procedure and the hospital team were unclear as to what steps should be taken regarding consent, which resulted in the procedure being delayed. Furthermore, a booked admission was cancelled by the care home giving the reason 'patient wanted

⁴ <https://www.nice.org.uk/guidance/ng12/chapter/Recommendations-organised-by-symptom-and-findings-of-primary-care-investigations#abdominal-symptoms>

⁵ <https://www.nhs.uk/conditions/Endoscopy/>

⁶ <https://www.legislation.gov.uk/ukpga/2005/9/contents>

to wait until July 'despite no evidence to explain how Mr V had made that decision and no record of multi-agency discussion between the carers, GP, hospital and community learning disability team about this decision, which should have been made under the best interest's framework of the Mental Capacity Act 2005.

There was a lack of knowledge in the endoscopy team at the acute Trust in regards to best interest decision making and understanding the Mental Capacity Act. Despite the lack of knowledge, advice and support was not sought from the safeguarding team who lead on the Mental Capacity Act or the Learning Disability Liaison Nurse in post at the time. There is no record of why Mr V did not have a best interest's decision made or whether a less restrictive option other than endoscopy under sedation was considered by clinicians to investigate the presenting symptoms. The hospital Learning Disability Liaison Nurse was not consulted to support Mr V and the staff with the care options and delivery. Timely investigations on the cancer pathway were delayed due to medical staff waiting for consent to undertake these by Mr V's family although there is no record of any legal powers of attorney/deputyships to mandate this.

While it is of high importance to gather the views, and wishes of family and others close to the person requiring a best interest's decision, this must be balanced with the risk to the person in delaying an important decision if they cannot be contacted. In contrast to the importance placed on contacting family, the carers of Mr V were not considered as part of best interest's decision making despite their long-standing relationship with Mr V.

Best interests decisions do not just involve family, the Mental Capacity Act Code of Practice⁷ states that "if it is practical and appropriate to do so, consult other people for their views about the person's best interests" "In particular, try to consult: anyone previously named by the person as someone to be consulted on either the decision in question or on similar issues, anyone engaged in caring for the person, close relatives, friends" "For decisions about major medical treatment or where the person should live and where there is no-one who fits into any of the above categories, an Independent Mental Capacity Advocate (IMCA) must be consulted.

An Independent Mental Capacity Advocate (IMCA) was not appointed in lieu of family being unavailable, which was Mr V's right under the Mental Capacity Act 2005. The NHS has a responsibility to refer to the local authority to provide an IMCA to safeguard the person's rights where the eligibility criteria is met, as it was in this case. The Office of the Public Guardian document 'Making Decisions'⁸ states an example of when an IMCA should be instructed is where 'there are reasons which make it impractical to consult with the family member or friend'

No decision was taken on Mr V's behalf until he was admitted some months later as an emergency.

⁷ <https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>

⁸

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/365629/making-decisions-opg606-1207.pdf

Coordinated Care

On 06 July 2014, Mr V was admitted to hospital, via the emergency department, with a perforated bowel caused by cancer in his bowel. On 17 July 2014, Mr V underwent surgical intervention to remove the mass. The post-surgical plan was to follow up Mr V, however, at the time of this surgery, there was no formal referral pathway to the Cancer Specialist Nurse. Normally someone who has had this treatment would be followed up by a specialist nurse from the acute Trust. However due to issues with the referral pathway, which have since been resolved, the nurse was not notified of the need to follow up Mr V. This, combined with a series of missed appointments meant Mr V's care was not followed up as it should have been. There was no identified professional leading and coordinating the care for this very vulnerable person who could not speak for himself.

The S.I. investigation by the acute hospital found that chemotherapy is sometimes indicated for the type of cancer Mr V had, the multi-disciplinary team discussion as to why Mr V was not suitable for chemotherapy was not documented. While it is likely this was decided due to his co-morbidities and the slim chance of it being beneficial, there is no record of this decision being discussed with family, carers or an IMCA as part of best interest's decision making.

Although Mr V was reviewed in the outpatients clinic a year later, there is no record of the agreed follow up scan occurring until two years later. This scan identified metastases which means the cancer, which begins in one part of the body, then spreads to other areas.⁹

Communication

The follow up plan for after care and review appointments were not made clear to the staff caring for Mr V at his home. Carers believed the reason for no further treatment was that the initial treatment had cured Mr V. They were told to liaise with the GP for further information and support although there was no clear plan for the GP role following discharge from hospital.

The carers in supported living knew Mr V very well and provided good care and support within their scope and limitations of their role. However, they did not have clinical training or an identified lead professional to manage information which they felt impeded their understanding of Mr V's condition as well as impeding their ability to challenge clinicians further on follow up treatment plans on behalf of Mr V.

There was confusion about booking clinic appointments and some appointments were cancelled in error. A booked appointment for follow up review for Mr V was cancelled by the home so that Mr V could go on holiday, there are no records to show this decision was made under the best interest's framework set out in the

⁹ <https://www.nhs.uk/conditions/cancer/>

Mental Capacity Act 2005. No records show any dialogue took place between the hospital and the home about Mr V's missed or cancelled appointments despite Mr V's clear vulnerability in being unable to make the decisions to attend himself.

There was a lack of coordination overall of Mr Vs follow up and after care following his initial diagnosis and surgery. The NHS Serious Incident Investigation (conducted by the acute Trust) showed Mr V was referred to the Clinical Nurse Specialist for follow up according to cancer network guidelines but no Clinical Nurse Specialist appointment was booked due to a lack of a formal referral pathway to the nurse at that time.

Confidence of unqualified care staff to respectfully question and challenge professional decisions

There is evidence throughout the chronology and from verbal reports from the staff who knew and cared for Mr V that information that was passed onto them regarding Mr V's care plan was not always accurate or in an understandable format for someone who was not a qualified health professional to understand.

The care staff reported that they had known and worked with Mr V for over 5 years and knew him well, they knew his personality and his communication style including his nuances of communication. They reported that they often did not have the confidence to challenge qualified professionals on clinical decisions or care and treatment plans. They described feeling at times that their knowledge of Mr V was not sought by qualified professional involved in Mr V's care.

This lack of partnership working between carers and health professionals had a negative impact on the quality of care provided to Mr V as he was unable to advocate for himself and was reliant on those around him to do so.

Quality of discharge information

The discharge summary from the hospital was not specific regarding follow up treatment and, therefore, open to the misinterpretation shared by the carers about his condition. The discharge information was a missed opportunity to agree who would be the lead professional to coordinate the care for Mr V on discharge from hospital.

4.3 Drawing together of the key themes

The Mental Capacity Act 2005 is law and was not followed by the services involved in Mr V's care. As a result, MR V did not benefit from the protections offered by this legal framework. The clinical staff did not follow the law to make the medical

decisions for Mr V and the care staff did not follow the law when deciding on Mr V's attendance at appointments.

The learning event found that unregistered care staff experienced a lack of acknowledgement by health professionals of the valuable knowledge and role in caring for Mr V. This, combined with a lack of understanding of the Mental Capacity Act, meant valuable knowledge was lost in decision making on behalf of Mr V and added to delays in investigation and treatment.

Qualified professionals should ensure they obtain information from those who know the person best, which includes paid care staff, when making assessments, interventions and discharge plans for individuals who lack capacity to make their own decisions about care in line with the statutory Code of Practice for MCA.

It was apparent from the discussions with the care staff at the learning event that unregistered care staff experienced a perceived imbalance of power when dealing with health professionals. This is consistent with a finding in the Safeguarding Adults Review for Adult W¹⁰ who also had a learning disability. Carers have been found to lack confidence in challenging and questioning qualified professionals in respect of health care plans and decisions made by those professionals. Many Safeguarding Adults Reviews nationally as well as locally have highlighted the need for multi-agency escalation and resolution procedures and such a procedure was available locally. Nevertheless, it is reasonable to suggest staff require training and support to use escalation and resolution procedures and also, the issue has to be identified by staff as a safeguarding issue to invoke them. At no time was a safeguarding concern raised in relation to Mr V by anyone involved in his care. In the delays and confusion around decision making, neglect of Mr V was not recognised until the LeDeR review was completed.

This review also raised issues in regards to the quality and effectiveness of GP and hospital appointments for people with complex needs such as Mr V.

The GP involved in Mr V's care pointed out that "it is hard to overstate the importance of Mr V being brought to his appointment by someone who knew him really well, as often people with a learning disability are accompanied to appointments by a care worker who doesn't know why they are there and the quality of the consultation is based upon the knowledge and skill of the person who brings them in. Often the care worker assumes the GP knows why the person is there and they don't"

¹⁰ <https://www.camden.gov.uk/documents/20142/25239190/Adult+W+SAR+-+Executive+Report.pdf/1dccf979-e12e-cdb0-b62e-55db88bb7b91>

This highlights the need for unqualified care staff to have training on how to support people with complex health needs to health appointments and to have extra support from their managers in these cases via supervision.

When a person is supported by care staff to a health appointment they must be accompanied by a member of staff who knows them well and they should take with them current and up to date health information. Unless it is an urgent matter, every effort should be made to coordinate appointments with the availability of the named carer.

It may not always be possible for a person with Mr V's complex health needs to be accompanied by a carer who knows them well but there should be a written brief from the care provider to support the clinician conducting the consultation with as much up to date information as possible.

One of the ways in which this can be done is by use of a one page sheet of information or by using a health or hospital passport. A health or hospital passport is a document that gives an overview of the person's medical needs as well as ways they like to be communicated with and information on ways to support the person with medical interventions.

These forms of documentation however are only as useful as the information within them and therefore this information needs to be current and up to date.

Advocacy and care co ordination

It was apparent from the attendees at the review meeting and from studying the chronology that there were several different agencies involved in the care of Mr V as well as the involvement of care staff and managers at Mr V's home.

Discussion was held looking at who/what agency was taking responsibility for overseeing Mr V's care throughout the chronology.

In the latter part of the chronology it is evident that there was more effective care co-ordination but it is not apparent in the early part of the chronology that any one agency or person was taking an oversight or lead in the co-ordination and follow up of all aspects of Mr V's care.

The participants at the review meeting discussed the importance of having at least one agency or professional taking responsibility for the oversight of someone with complex vulnerabilities such as Mr V.

The role of clinical and social work within the Community Learning Disability Team could have provided a coordinating and supporting role between the care staff and the health professionals for Mr V. While there is plenty of evidence to demonstrate the involvement of the social worker and learning disability nurse in providing excellent end of life care to Mr V, their role during the stages of investigations

between 2014-16 was not apparent. However speech and language therapy, occupational therapy and physiotherapy services from the community learning disability team were involved at the earlier stages of Mr V's care.

Assumptions were made that each agency was supporting Mr V in the best way possible (which they were) but because there was no "helicopter view" with no single agency/professional taking that high level oversight then opportunities for intervention and key stages were overlooked, for example finding out why appointments were missed/cancelled and ensuring correct after care information was gathered.

Discussions at the review meeting looked at the way in which often adults who do not attend hospitals or clinic appointments are marked down as DNA (Did not attend). However, in cases such as that of Mr V he was totally reliant on his carers to make and attend all health appointments so he had no choice or understanding in attending or not attending for appointments. Therefore, he 'was not brought' rather than 'did not attend' and this should warrant further enquiry from the agency sending an appointment.

5. Examples of good practice

Throughout the initial LeDeR review, from information gathered at the learning event and information seen within the Serious Incident (S.I.) investigation report from the acute Trust there are many examples of good practice, which are presented below including quotes.

- When Mr V was first identified as being unwell, noted by care staff, and having bowel problems the information from the LeDeR review state that the GP made an immediate referral to the gastro enterology team under the 2-week rule referring process. This is a process where the GP makes a referral to the local acute Trust for an urgent appointment because the person's symptoms indicate they may have cancer.
- The GP was someone who had known Mr V for a number of years and was a consistent person in Mr V care network.
- The team of care staff at Mr V's home was reported to be stable and staff knew Mr V for many years
- "The Gastroenterology Team tried to facilitate an urgent procedure through an inpatient admission, and the GP also followed up with the hospital team when required".
- "In addition, it was evident from the medical notes that the patient was very well managed following his acute diagnosis of a perforated bowel, and that the emergency surgery was undertaken immediately once it was deemed to be in the patient's best interests. Furthermore, the patient was discharged following the surgery in good health, and his complex needs were well met postoperatively."

- The care staff at Mr V's home were not trained clinicians but they were proactive in requesting clinical advice and support.
- Staff at the care home requested help and guidance on how to manage the patient clinically and sought this at every opportunity.
- It is evident that the Community Learning Disability Nurse from the local CLDT was very involved in supporting Mr V and the care staff. "The Community Nurse for Learning Disability provided guidance and support to staff whilst they were caring for the patient."
- Towards the end of Mr V's life he was cared for at home with support from the palliative care team and it was reported that "The palliative care nurse specialist [CNS1] made over 200 contacts to the patient and carers during that part of the patient's pathway and on one occasion the nurse is noted to arrive at the residential home 10 minutes after receiving a call from staff – this nurse provided exemplary care and support. The palliative care team also ensured that the patient's carer's emotional needs were met when they were providing end of life care. "

6.Summary and conclusion

People with a learning disability are subject to extreme health inequalities with a gap in life expectancy of 26 years for women and 20 years for men (LeDeR Annual Report 2019). Mr V was a man with severe and profound learning disability, he had impaired sight and hearing and he was totally reliant on those around him for all aspects of his care and support and daily living activities. He was unable to speak up for himself and needed someone to advocate on his behalf.

From reading reports, meeting with Mr V's care staff and meeting with clinical and medical staff involved in his care it is apparent that Mr V was loved and well cared for.

There was a high-quality network of health and social care professionals and care staff supporting Mr V.

What is striking from conducting this review is that although the network around Mr V was good there seems to be a lack of 'informal' advocacy for him. The thing that seems to be missing is who took the role of speaking up for him. Whether a person has a formal IMCA or Care Act advocate or not, those working with vulnerable people should also see advocacy as part of their role in supporting the person.

Person centred care is essential when supporting someone with such complex needs as Mr V and there is evidence that the care he received was person centred. What is absent was a lack of oversight and coordination of his care.

In children's services when a child has additional needs there is an early health assessment (previously known as common assessment framework) which is a

holistic assessment of the young person and all agencies involved in their care¹¹. All agencies involved in the child's care come together to nominate a lead professional usually the person whose role has most involvement with the child. It is this person who then oversees the care coordination of the child and holds the network to account.

Mr V was an adult however it could be said that he had some similar needs to a child as he was not able to advocate for himself. This is a system that should be replicated.

Changes made by the care provider

In regards to supporting people with complex physical disabilities and complex health needs to appointments the manager of the placement where Mr V lived reported that it is the responsibility for service managers to follow up issues when service users are unwell. They take on this responsibility and it is not left solely to the care staff. The managers now immediately contact the Community Team for People with a Learning Disability (CTPLD) and work as a team not separate organisations.

The care provider reports that now if a person being cared for in their organisation is presenting with health problems then the social worker is informed straight away and if a person has complex needs and requires ongoing case management then they will receive more intensive support.

Changes made at the acute Trust

The acute Trust has incorporated information on the MCA into adult safeguarding level 3 training as set out by Adult Safeguarding: roles and competencies for healthcare staff (August, 2018). A specialist learning disability liaison nurse is in post and has developed clear networks within the Trust to support staff.

The acute Trust has actioned work to ensure that discharge summaries and letters for people with similar needs as Mr V are simplified and that they facilitate better communication with other agencies.

When providing training on MCA and DoLS the acute Trust recommends that these simplified discharge summaries are used as part of the training.

The acute Trust is using the case study of Mr V as a learning opportunity for reflection and supporting the need for effective communication between all agencies. The internal Serious Incident report as an outcome of Mr V's case is being used for training and reflection with the colorectal surgical team.

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https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/779401/Working_Together_to_Safeguard-Children.pdf

The acute Trust has now put in place a robust nurse led follow up pathway for the management of patients follow up and oversight.

Changes made by the CCG

Work has been done around the MCA with GP's and supporting GP's to understand the application of the MCA. Also, there has been work to embed an MCA template onto the GP electronic records system known as EMIS.

There has been a focused piece of work around improving uptake and undertaking of annual health checks for people with a learning disability as well as improving coding of people with a learning disability on the GP electronic records.

7.Recommendations

Advocacy

All staff who provide care and support for adults with complex needs with a severe and profound learning disability should see themselves as the person's advocate, this includes knowing when to refer for specialist independent advocacy.

Assumptions should not be made that someone else is taking on the responsibility to advocate for the vulnerable person and it should not be a role just for specialist advocacy services.

<p>Recommendation 1: The Acute NHS Trust should monitor and ensure they are making IMCA referrals when someone is unable to consent to their treatment.</p>
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Care Staff who do not hold a professional registration

For providers of care to ensure that staff without professional registration who support people with complex health needs and severe and profound learning disability are recognised as having valuable knowledge and understanding of that person by those who have professional registrations.

Care staff who do not hold a professional registration need training, development, managerial support and supervision on how to support a person with complex health needs to GP, hospital and clinic appointments.

Care staff who do not have a clinical background and who are supporting people with complex health needs and physical disabilities should have training on how to care for people with these specialist needs.

Recommendation 2: The Integrated Community Learning Disability Team should consider developing training and making the offer available to Learning Disability provider services regarding supporting a person with their health needs.

Hospital passport/health care plans/one page grab sheet

Discussion was had at the learning event in regards to people with severe and profound learning disability with complex health needs having quality health appointments where up to date health information for the person needs to be presented. If the staff supporting the person to an appointment do not have in depth knowledge of the person's health issues, or have accurate up to date health records and documentation then the appointment time maybe wasted.

Recommendation 3: For all hospital passports/health care plans to be kept up to date and regularly reviewed. For people with severe and profound learning disability with complex health needs to have an up to date one page health profile to support GP and hospital appointments.

Care coordinator

Where a person who has a moderate to severe/profound learning disability and has complex health needs and receives care and support from more than one agency then a decision must be made by all involved agencies on identifying a key worker/named person who will take the responsibility of high level overview of the person's care.

The person identified in this role should take responsibility for coordinating multi-agency meetings and ensuring that need to know information is shared between all involved agencies.

Recommendation 4: Develop a system that ensures a lead role/professional is agreed to coordinate care between the Acute NHS Trust and community services for a person with a learning disability.

Application of MCA

In order to safeguard a person's rights and ensure the least restrictive options are used and reviewed an application should be made for a deprivation of liberty.

Recommendation 5A: Health and social care providers should ensure that all clinical staff have access to support and advice on the MCA in addition to receiving training and written guidance.

Recommendation 5B: Health and social care providers should ensure that MCA policies are linked to relevant policies such as consent.

Recommendation 5C: Health and social care providers to ensure that the MCA profile is raised and continually refreshed.

Recommendation 5D: Health and social care providers, including CCG's, should ensure that the relevant organisational lead for MCA and DoLS is known throughout the organisation and that the person in this role should be available and able to provide expert guidance and support on any issues related to MCA and DoLS.

Escalation of concerns

From reports and discussion at the learning event it is noticeable that there was a lack of enquiry into the outcomes of Mr V's treatment and follow up. Opportunities were missed for escalation of concerns in regards to carers not knowing fully his follow up treatment.

Recommendation 6A: Organisations who provide care for people with severe and profound learning disability with complex health needs should have clear accessible policies and procedures for staff to escalate concerns.

Recommendation 6B: Within staff supervision "Escalation of concerns" should be raised as a topic for discussion.

Recommendation 6C: The CSAPB to seek assurance that the Multi-Agency Escalation and Resolution Procedure is being utilised by partners.

Professional Curiosity

There should be curiosity if a vulnerable person, who is reliant on others for all their health and social care needs, has not been attending an appointment when there are issues with their health and care.

Missed appointments for this group of people should be recorded as "was not brought" as opposed to "did not attend" with a clear set of actions to follow this up

Recommendation 7: Health and social care service providers must have a robust "Was Not Brought Policy" that is specifically targeted at adults who are unable to

advocate for themselves and are totally reliant on others to support them to health appointments.

Appendix 1

Chronology as gathered from the LeDeR review

Mr V was reported as being unwell in July 2013

17.07.13 Admitted to Hospital with Sepsis of unknown cause. Had a chest x-ray. No abdominal investigations done as no indication at this time according to hospital records. Discharged on the 19 07.13

02.08.13 Diarrhoea

07.01.14 Physiotherapist from CLDS highlights 10 kg weight loss over an unknown period of time to keyworker and GP

08.01.14 Keyworker reports weight loss to GP , books an appointment

21.01 14 GP appointment Referral made for two week wait due to suspected GI cancer. Manager at supported living advised to call GP in two weeks if no appointment.

29.01.14 Two week wait referral confirmed received at the Hospital

04 02.14 Gastroenterology clinic appointment at the royal free. Recommended an upper and lower gastro-intestinal (GD Endoscopy assessment. Will need to be completed under Propofol sedation, Elective list was fully booked until May. Doctor recommended an admission to be arranged and it be completed on the emergency list

07.02.14 Fever. Paracetamol prescribed and appointment for 3 days' time

10.02 14 Attempted urine test but unable to collect sample due to incontinence. Fever treated with broad spectrum antibiotics

20 02.14 Hospital Letter sent stating Pre-assessment unit appointment booked for 03.03.14

03.03.14 Hospital/ CLDS Pre-assessment unit appointment. Reported attended by home staff. Waiting decision by sister and advocate.

14.03.14 GP received letter from clinic visit on the 4.2.14

08.04.14 Gastroenterology clinic appointment at the Hospital. Re-iterated plan for upper and lower GI Endoscopy under sedation and stated a best interest decision would have to take place. No documentation that investigation or best interest meeting occurred.

29.05.14 Diarrhoea, home and GP had not heard from Gastroenterology since letter received on the 8.04.04. GP contacted Acute Liaison nurse at the Hospital to organise best interest decision.

11.06.14 Due to be admitted under Gastro-intestinal team at the Hospital on 11 June

Recorded in hospital records as being cancelled on day staff from Kelly Street who wanted to postpone in until next month, but no reason documented,

30.06.14 Blood in stool. A new 2 week wait referral was completed by GP as no further actions occurred from first referral

07.07.14 Admitted to Hospital rectal bleeding and a UT. CT scan on 08 07.14 reports a large mass in bowel and hernia 16.07.14 discussed in cancer MDT and recommended a resection. And sigmoid colectomy took place on 7.7.14 Sister did not have relevant legal right to make this decision, an urgent best interest decision should have been made instead. Developed a respiratory infection post operatively and recovered. Follow up CT on 26.07.14 showed a hernia.

Discharged from hospital on the 08 08 14. Not for further management of tumour. For follow up appointment in 6-8 weeks.

10.10.14 Follow up appointment booked but then cancelled by home manager in error as they believed it was to discuss surgery.

20.11.14 No follow up appointment booked yet GP contacted hospital Follow up appointment booked for 12.12.14

12.12.14 Gastroenterology clinic appointment at Hospital Discharged from surgical clinic, not suitable for chemotherapy- Referred to Clinical nurse to be followed up per cancer network guidelines No CNS appointment booked. Unclear as to reason

10.02.15 Full blood count — no abnormalities

14 04.15 Eczema flare up

22.04.15 DOLS assessment completed but unclear what for. No documentation on Council or GP system

20.08.15 Skin lesion

14.10.15 Letter to hospital surgical team from GP asking for hernia follow up

14.12.15 Hospital Gastroenterology Clinic appointment at the Hospital Review of the hernia - no follow up necessary. Referred to CNS again for colorectal cancer to organise routine follow up CT scan. No CNS appointment booked Unclear as to reason

05.05. 16 Chest infection

23.06. 16 Rash

19 07.16 GP advised carers to continue to monitor bowels. GP requested a follow up appointment and CT scan from general surgery clinic

28.07.16 Email from medical secretary to CNS requesting follow up from GP letter. CNS requested an urgent CT, bloods and appointment in clinic, this was Cancer CNS first involvement in this case

15.09.16 Hospital CT scan of chest, abdomen and pelvis completed. Shows multiple mass's stage 4 in both lungs.

05.10.16 Hospital Clinic appointment with Gastroenterology given results of scan, informed there were no interventions that were appropriate and Mr V would be referred to Palliative care team.

6.10.16 CLDS Communication between home and CLDS requesting support as Mr V was sent home

27.10.16 CLDS Entry documenting a conversation with Colorectal CNS. CNS had reviewed surgery from 2014 and reported that V initial cancer diagnosis (in 2014) had been acute; the tumour couldn't be resected completely due to positioning close to blood vessels, and the cancer had all of the features that suggested that cancer recurrence would be likely for V. It was suggested that support staff had not been aware of this and were under the impression that V operation had cured him. CNS reported that the information on discharge was complex and may not be easy for non-specialist to understand. Also, discussed decision not to have chemotherapy — decided that he was not fit for this but this may have warranted a best interest decision. Also, discussed decision to not operate on hernia — decided he was not medically fit also, but was queried whether this should have been a best interest decision, Improved communication necessary -Giving people information in a format mat they understand. Best interest decision should be taken when warranted

30.10.16 Anticipatory medications prescribed at request of palliative care team
Morphine sulphate 2 5mg

Midazoiam 2 5mg

Cyclizine 50mg

Hyoscine 60-120 mg over 24 hours

2.11.16 Telephone review home deputy manager. Mr V is still attending day centre, Pain seems well controlled with Butrans and PRN Paracetamol Continues to eat and drink normally- Discussed rationale for injectable medication — staff are not trained to administer these but have a secure place to store them. DNAR form to be completed by home staff and dropped in to be signed by GP. booked for flu jab on 8.11 18

07.11.16 CLDS nursing team attended home staff meeting and discussed V diagnosis and prognosis and answered their questions

14 11.16 Given Flu jab

21.11.16 CLDS CLDS nursing met with Mr V's mother and sister to discuss diagnosis and care needs. Agreed to keep them updated with any further information

21.11 16 CLDS CLDS nursing and palliative care attended home staff meeting

21.11.16 Discussion with sister and mother. Discussed the delay between request and CT scan, GP agreed to look into this and informed them If he heard anything, Discussion around family making preparation for their funeral wishes.

25 11.16 CLDS Social worker planned to meet with home staff and family but family did not attend. Follow up phone call with family to discuss if they wanted to make a complaint regarding communication from hospital and to plan for funeral arrangements. Mr V sister told sw to liaise with home manager regarding the complaint as she was traveling back to and would not have time to complete the form

01 1 2 IS CLDS nursing and palliative care attended home staff meeting to discuss Mr V support needs

02.12.16 CLDS Increased funding for care at home as Mr V would not be able to attend day centre as often before. Option for FastTrack CHC funding discussed between CLDS nursing social care and palliative care but not appropriate at this time

5.12.16 Support workers report several episodes of Mr V appearing to be in pain. Paracetamol no longer appears to be effective. GP prescribed Co-codamol 15mg and advised he may need additional laxatives if used regularly.

07.12 16 CLDS nursing meeting with home staff. Discussed ways to support staff and Mr V. Discussed Mr V increased presentation of pain. Increase in pain medication organised with GP

21.12 16 CLDS nursing attended meeting with home to discuss care and updated palliative care plan documentation.

23 12.16 Urgent request from palliative care Butrans prescribed by GP

03.1.17 Telephone call to home Confirmed Butrane increased to 10

1.2.17 Telephone call from home. Staff noted weight loss over last year- GP reports likely linked to cancer diagnosis. Prescribed supplements and Given advice to attempt to increase food intake

02.02. 17 CLDS Discussion between CLDS nursing and home Mr V is losing weight. They have spoken to GP and been given advice.

10.02.17 CLDS nursing visit to home. Discussed decreased appetite and pain medication

17.02.17 CLDS Social worker discussing with home staff. Issues with bed and a repair arranged

20.02.17 CLDS to home staff palliative care team and GP over weekend as he became breathless and stopped eating,, GP prescribed Clarithromycin for a suspected chest infection. Mr V improved the next day.

21.2.17 Telephone call to GP from home reporting loose stool Had started Clarithromycin for a suspected chest infection and was due to finish on 25.2.17- GP advised to finish antibiotic course and stop macrogol laxative.

23.2. 17 Telephone call from home to check medication — GP confirmed to stop Macrogol as still having loose stool.

24.2.17 Urgent email from palliative care nurse requesting Oromorph PRN and Lorazepam PRN

27.2. 17 Telephone call from home loose stool now settled advised to restart Macrogol given constipation is a baseline and Oromorph started

01.03.17 CLDS Bereavement support provided by CLOS psychological therapies to staff at Kelly Street.

7 3.17 Telephone call from home, High temperature, Given Oromorph but no effect, Called 111 and doctor visited. No further action necessary and started to settle

8.3.17 Telephone call from palliative care- Concerned about ongoing high temperature but otherwise seems ok Telephone call to home – staff are concerned he is in pain, Concerned about urine infection but unable to a sample as wears pads Trimethoprim prescribed 200mg twice a day 7 days course.

10.3 17 Telephone call from home, Loose stools due to antibiotics, advised to stop Macrogol until bowels open a day- Otherwise improving.

17.03.17 CLDS CHC fast agreed. Decision agreed to support Mr V at home rather than a placement

22.3.17 Telephone call from home No bowel movement for 2 days Not eating last 2 days and doesn't like supplements, It not opened tomorrow then to call back to consider increasing laxatives

23.3.17 Telephone call from home. Still not opened bowels,advised to increase Macrogol to 2

5.6.17 Telephone call from home discussing use of cream. Rash has now cleared up. GP advised to continue using for one week after rash cleared up then stop Loose stool

14.06.17 CLDS Discharged from SLT as back to baseline

19.6.17 Telephone and face to face assessment. Swollen and pus discharge from left elbow. GP reviewed and there was no pus. Diagnosed and treated ringworm with Clotrimazole cream.

3.7.7 Telephone call from home. Dry cough last few days. No other concerns. Likely related to lung cancer diagnosis. Liaison with palliative care — increasing pain levels therefore increased Fentanyl to 25mca

10 7.17 Telephone call — worsening ringworm. Prescribed Miconazole cream.

13 07.17 CLDS increased Fentanyl dosage to 25mca as Mr V was in more pain.

14.7.17 Liaison with palliative care — increase Oromorph to 15mg PRN 1 hourly.

17.7.7 Telephone call from home. Rash around injection mark from morphine but settling now. Generally worsening, decreased appetite and increase discomfort

24.7.17 Telephone call from Home. Concerned about swelling feet. Telephone assessment but no concerns identified. Advised to discuss with district nurses or palliative care team and then to contact GP if further concerns or swelling spreads. Telephone call from home, One instance of vomiting following coughing fit. Telephone review x 2 to monitor but more settled. Palliative care nurse reviewed

25.7.17 Liaison with Palliative care nurse — she advised a visit with the regular GP as Mr V is deteriorating and will likely pass away within a few weeks. Home visit for review- No impression of acute infection but rather general deterioration

31.07.17 Mr V had an episode of struggling to breathe. Palliative care team were called and arrived within 10 minutes, administered some medication and Mr V settled down. CLDS nursing and social work also supported staff at Kelly Street Arranged for Carelink nurses to come and support home staff

31.7.7 Liaison Palliative care — increase in medication due to distress — Hyoscine butylbromide 20mg/1ml solution for injection — 20mg 8 hourly. Midazolam 10mg/2ml

1.8.17 Liaison with Palliative care — Mr V rapidly deteriorating - additional medication - Hyoscine butylbromide 600mcg/1ml

03.08.17 CLDS + GP Mr V passed away at 05:15 from lung cancer metastasis resulting from colonic primary cancer.

REPORT ENDS