Sunderland Safeguarding Adults Board

Safeguarding Adults Review

'James'

Executive Summary

June 2025

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Contents

Introduction

1.1 James was a 50 year old man with a learning disability and autism. James died in December 2021; the cause of death was pulmonary embolism. The Coroner stated that whilst his death was from a natural cause it may have been hastened by the effect of confusion around his prescribed medication due to a lack of collective communication between all those involved in his medication.

1.2 Following a referral for a Safeguarding Adult Review, the Sunderland Safeguarding Adults Board (SSAB) Safeguarding Adult Review Sub-Committee held a scoping exercise regarding the information known in relation to James. The Scoping Panel concluded that the criteria to undertake a statutory Safeguarding Adult Review (SAR), in line with the SSAB SAR Protocol, were not met. A recommendation that a discretionary SAR be commissioned was taken to the Independent Chair of the SSAB who, after reviewing the information collated by agencies, was in agreement that a discretionary SAR be undertaken.

Terms of Refence

2.1 A multi-agency panel was established by Sunderland SAB to conduct the review and report progress to the Sunderland SAB. Membership included an Independent Reviewer and representatives from key agencies with involvement.

2.2 The purpose of the review was to identify multi-agency learning and wider systems issues around the process of the transfer and continuity of prescribed medication when a person moves from one area to another.

Methodology

3.1 The SAR in Rapid Time approach was utilised for this review. Agencies involved with the adult provided scoping reports and chronologies which were then analysed to produce an Early Analysis report which included a summary timeline, key episodes for analysis, early analysis and questions in relation to each episode, and the drawing out of wider systems findings.

3.2 The Early Analysis report provided a framework for multi-agency analysis and reflections, which included practitioners who had worked directly with James. A Systems Findings report was then produced and recommendations made.

Family Involvement

4.1 James' family were invited to review and contribute to the final version of the Systems Findings report, they also chose the pseudonym used. James' family said they appreciated the time and effort that had gone into preparing the timeline, sequence of events and actions that were taken, that James' case was complicated and involved a number of agencies and individuals, and that the report demonstrated the seriousness and thoroughness of the review.

4.2 They said that they understood the pressure that all of the people involved with James were under through the process of his move to Sunderland, his on-going care and his final days. The family acknowledged that it could be difficult at times for James to convey his thoughts, feelings and needs to staff in a positive way. The family felt that

the people responsible for James' care in both Redcar and Sunderland were hardworking (and most likely overstretched), under pressure and facing conflicting demands. Despite this, the family felt that they did continue to care and never questioned the fact that professionals wanted to do their best for James and had his best interests at heart.

4.3 The family reported that unfortunately his mother was not of the same opinion and they said that once James passed away, his mother simply gave up. She was convinced that someone was responsible and in her last days she continued to refer to this. She also carried a 'mother's guilt' that she could have done more for James and that somehow this was her fault. She did though hope some lessons would be learnt and the family said that the report would have given her some comfort.

4.4 James' family felt that the review had answered the questions and responded to the themes they themselves had identified. They said the report has highlighted the system failures and they maintain some confidence that things will change. However, 'they wait to be convinced that lessons have been learnt, or more importantly, applied'.

Background Information and Summary of Events

5.1 James was a 50 year old man with a learning disability and autism. James lived in the family home until he was 18 and then moved through a variety of residential placements, with a brief admission to a secure hospital, followed by an inpatient facility providing assessment and treatment services for adults with learning disabilities.

5.2 In 2011, James transferred to a specialist setting for people with a learning disability and challenging behaviour. Following an initially settled period, his behaviour gradually deteriorated, including significant staff assaults, and in 2014 he was detained under the Mental Health Act. He was discharged to a placement for people with learning disability and mental health conditions, provided by the Priory Group in the Borough of Redcar and Cleveland, where he resided until August 2021.

5.3 From 2020 James expressed a strong desire to move to his own flat. He became increasingly frustrated at the time it was taking to find suitable accommodation (exacerbated by the covid-19 pandemic and availability of suitable provision) and there was a significant and sustained deterioration in his presentation including frequent and significant staff assaults, and significant damage to property.

5.4 A placement provided by Swanton Care, in Sunderland, was identified as an appropriate alternative provision. James was jointly funded by health (Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV)) and the local authority (Redcar and Cleveland Borough Council), with TEWV acting as the lead commissioner. Swanton Care assessed James and a four week transition period commenced in early July with staff from Swanton shadowing staff at the Priory Group.

5.5 At Swanton, James had his own self-contained basement flat within the home and a support package of 1:1 day time with shared staffing during the night. James initially settled well into the home. He was able to use a 'top up' mobile phone, prepare meals (frozen, 'ready-made'). James liked to go to the shop on a daily basis to purchase a newspaper, Mars Bar and coca cola. He liked to draw, watch films and listen to music.

5.6 James had a Positive Behaviour Support plan in place at the Priory Group and this was shared with Swanton. James had good functional communication skills but experienced more difficulty with higher level abstract language. James had a strong preference to be as independent as possible and for routine. James was described as having significant difficulties with social understanding and he placed unreasonable expectations on himself to be independent. James found it difficult to understand and process his own emotions and to talk about these matters with others. He experienced difficulty with impulse control and, as a result of these difficulties, could quickly become frustrated resulting in physical aggression and property damage.

5.7 In 2019, James had a left deep venous thrombosis. James was overweight and in 2021 had a BMI of 28.35 and a 10 year cardiac risk, gaining 2 stone during the covid-19 pandemic. James was supported by the Practice Nurse regarding weight management and cholesterol checks.

5.8 James's prescribed medication included the following (categorised under the broad headings of mental health and physical health medications):

Mental health medication

Risperidone – An antipsychotic medication used to treat the symptoms of some mental health conditions. In this case it was prescribed for aggressive/agitated behaviour.

Sertraline – An antidepressant medication known as a selective serotonin reuptake inhibitor (SSRI). It is used to treat depression, anxiety disorder, panic attacks and obsessive compulsive disorder. In this case it was prescribed for anxiety.

Pregabalin – An anticonvulsant medication used to treat epilepsy and anxiety. In this case it was prescribed for anxiety.

Promethazine – An antihistamine medication used to relive symptoms of allergies and known to have a sedative effect. In this case it was prescribed for restlessness and agitation.

Physical Health medication

Carbamazepine – An anticonvulsant medicine used to treat epilepsy.

Apixaban – An anticoagulant medication used to help prevent blood clots and reduce the risk of heart attack and stroke.

Atorvastatin – A lipid-regulating medicine, commonly known as a statin, used to lower cholesterol and prevent heart disease, including heart attacks and strokes.

Tamsulosin - An alpha-blocker used to treat enlarged prostate, and occasionally taken to treat kidney stones and prostatitis. Alpha blockers reduce blood pressure by relaxing blood vessels so blood can pass through them more easily.

5.9 When James moved to Swanton Care in August 2021, Swanton Care had been provided with James' Medication Administration Record when he moved which listed the medication he was prescribed. However, Swanton Care contacted the Redcar and Cleveland social worker on the 6th August to request a full list of James' medication, suggesting that there was a discrepancy in the medication he was supposed to be prescribed. There were further uncertainties about the dosage of Promethazine and clarity was sought from the Community Nurse. It appears that the uncertainties were resolved by the 12 August 2021.

5.10 James was registered with Surgery 2 on the 11th August 2021. Surgery 2 received a letter from the psychiatrist on the 24th August 2021 with medication listed as Risperidone, Tegretol, Sertraline, Pregabalin, and Promethazine.

5.11 The electronic transfer of patient records from James' previous surgery to Surgery 2 failed on the 25th August 2021. Surgery 2 requested paper records from the old surgery and these are received on the 8th September 2021 (28 days after registration). This meant that Surgery 2 were not fully furnished with James' medical information, including prescribed medication, for four weeks.

5.12 On the 6 September 2021 Swanton Care reported receiving a repeat prescription upon which "NOT NEEDED" was handwritten for the medications Apixaban, Atorvastatin and Tamsulosin. Neither the GP nor the pharmacy believed that either of their organisations had marked the prescription "not needed". It is unclear where this amendment happened and how it factored into the medication supply.

5.13 On the 7th September 2021 Swanton Care notified the pharmacy that the Apixaban, Atorvastatin and Tamsulosin were no longer needed. On the 20th September 2021 a Medication Administration Record was reportedly received by Swanton Care from the pharmacy which detailed Apixaban, Atorvastatin and Tamsulosin as 'discontinued' written by hand.

5.14 Apixaban, Atorvastatin and Tamsulosin remained on the prescription and continued to be ordered by Swanton Care. However, by the 18th October these medications had been removed from the Medication Administration Record and were not requested again based on the belief they had now been discontinued.

5.15 On the 29th September 2021 Swanton Care confirmed with the pharmacy that Apixaban, Atorvastatin and Tamsulosin had been discontinued following a medication review on the 2nd August 2021. Therefore, Apixaban, Atorvastatin and Tamsulosin were not administered to James for two months prior to his death.

5.16 James died in December 2021. There was a Coroner's Inquest which concluded the following: The cause of death was pulmonary embolism. The Coroner further stated that the death was from a natural cause which may have been hastened by the effect of confusion around his prescribed medication due to a lack of collective communication between all those involved in his medication.

5.17 A 'Learning from lives and deaths - People with a learning disability and autistic people' (LeDeR) Initial Review was also completed following James's death. The Review identified issues around medication for cardiac and circulatory problems not being included in the Consultant Psychiatrist's letter to the GP, and an electronic prescription being amended by hand (undated and unsigned). The LeDeR did not recommend a Focused Review but outlined actions in response to the issues identified.

Systems Findings

Supporting people when moving from one home to another and responsibilities during transitions

There was a four-week transition period leading up to James's move from the Priory Group to Swanton. However, the transition period was made difficult by covid-19 pandemic and distance between care homes (36 miles/1 hour). The plan did not go as expected with Swanton staff shadowing on seven days across the four weeks, and Swanton staff did not observe the administration of medication. Furthermore, the transition plan was unclear about who was responsible for what and lacked a multi-disciplinary approach.

During the transition period medication was reviewed and changes were made. When James moved, there was one week remaining in the four-week medication cycle and a new cycle of medication was delivered to Swanton on the day he moved in, however, James ran out of Sertraline and Pregabalin 20 days later.

Health commissioners have their own out of area protocol[1] which should have been followed by the health case managers in this case. The review panel reported that the North East are working on a Local Authority host Commissioner Protocol which sets out the rules and responsibilities of Commissioners in response to all of the services in that area, and within that protocol there will be references to people transitioning across boundaries into out of area placements. There is also an Association of Directors of Adult Social Services Local Government Association (ADASS) note for local authority commissioners that gives guidance on out of area placements.[2] Both the proposed protocol and ADASS note are additional useful documents that can be referred to in out of area cases.

Transition often refers to the transition of people with care and support needs to adulthood and the transfer from child to adult services. As a result, there is a lack of guidance around other types of transition, including moves from one placement to another. The review has also highlighted the added complexities to transitions when a person moves from one local authority to another.

Moving GP surgery and transfer of medical records for complex/vulnerable patients

James was registered with the new GP surgery nine days after he moved to Swanton. When a person is registered at a new surgery they cease to be a patient at the old surgery once the notification of re-registration is received, medical records are then transferred from the old GP to the new GP which can take up to 28 days.[3]

The electronic transfer of GP records failed in this instance. A patient summary was sent from the old GP to the new GP but contained no medication details, which suggested that James was not prescribed any medication. A letter was sent by the psychiatrist to the new GP thirteen days after registration which listed all of James's mental health medication[4] but not the medication prescribed for his physical health. The new GP finally received the paper records from the old GP twenty-nine days after registration.

This meant that the new surgery were not fully furnished with James's medical information, details of prescribed medication and medical history for four weeks, which resulted in delays in prescribing medication and confusion for all parties as to what James was prescribed. The new GP surgery reported during the review that a Patient Summary with the prescribed

[1] https://www.england.nhs.uk/long-read/learning-disability-and-autism-host-commissioner-guidance/
[2] Advice note - commissioning out of area care and support services
[3] How to register with a GP surgery - NHS (www.nhs.uk)
[4] Risperidone, Tegretol, Sertraline, Pregabalin, Promethazine

medication included, or a psychiatrist letter with all medication for both physical and mental health listed, would have been sufficient for the new surgery to prescribe James's medication.

Neither GPs were involved in the transition plan or process for James.

Delays in registering patients with a new GP can lead to additional delays affecting the continuity of healthcare provision. There also appear to be no special provisions for people with complex needs and vulnerabilities who are changing GP practice.

The electronic transfer of records is compromised when services use different IT systems leading to delays in sharing and transferring information.[5] The transfer of records can take up to 28 days which will impede continuity of healthcare, particularly for complex, vulnerable patients. A Patient Summary can help mitigate the risks bought about by this delay.

Depending on the systems being used, when a Patient Summary is requested from the system, after the patient has deregistered, prescribed medication is not included in the return unless the date parameters are adjusted to a date when the patient was registered. In either cases, a Patient Summary needs to be retrieved from the system before the patient deregistered in order that it includes prescribed medication.

A proactive approach which includes early communication with the identified GP practice that is going to take over the care is missing and it is the experience of social care providers that GP surgeries will not engage proactively. However, when an individual with complex and vulnerable needs, with a mixed pharmacology, early communication is essential in the transition phase, rather than relying on a reactive approach which may lead to gaps in care and prescribing.

Seeking clarification on prescribed medication

An apparent discrepancy in prescribed medication arose and further uncertainties about the dosage of Promethazine. A medication review took place on the day James moved. Later that month Swanton received a letter from the psychiatrist which listed James's medication as Risperidone, Tegretol, Sertraline, Pregabalin and Promethazine. This letter was also sent to the new GP.

In early September Swanton notified the new surgery that James was missing Apixaban, Atorvastatin and Tamsulosin. The surgery advised that they had no record of this medication and a few days later 'NOT NEEDED' was found hand written on the prescription (the note was unsigned and undated, and the source of the handwriting is unknown). On that basis Swanton informed the pharmacy that this medication was no longer needed and therefore Apixaban, Atorvastatin and Tamsulosin was not administered to James for the two month period prior to his death.

Whilst the review acknowledged that professionals were trying to be helpful when Swanton were attempting to verify James's prescribed medication, clarity should only be sought from the prescriber. The review highlighted the importance of understanding the roles of psychiatry and general practice. The role of the psychiatry is to review mental health medication and suggest changes to the GP; they do not prescribe the medication directly. The GP is therefore the prescriber of all medications.

Since this situation arose the Great North Care Record (GNCR) has been implemented which means that health professionals are able to access a live view of medication prescribed (both currently and historically). If a case like James's arose again now, the two GP practices would both have a live connection to the GNCR in terms of what was prescribed and if a community nurse, or other professional, was checking they would be able to view the current list of

[5] Old GP surgery used SystmOne, the new surgery used EMIS

medication that the GP was prescribing at any point, including on the day of transfer of the patient.

Verifying medication changes

The “NOT NEEDED” and “DISCONTINUED” hand written notes ultimately led to James’ physical health medications being removed from the medication record and not being administered in the two months before his death.

Swanton Care confirmed during the review that they now only accept medication changes by formal written communication from the GP or psychiatrist.

It is difficult to identify the exact system issues in the instance of the notes on the prescription and MAR sheet as the review has not been able to verify the source of these handwritten notes. However, there is a clear process for the cessation of medication which can only be completed by the GP, as the prescriber (or the patient themselves, if they have the mental capacity to make such a decision) yet there appeared to be a lack of understanding by Swanton about the process for discontinuing medication, and this links to the understanding about the roles of psychiatry and general practice.

The review identified that there is no failsafe in place for vulnerable people and those that lack capacity in areas related to their health. Whilst there is a system in place to alert GPs to patients ordering medication sooner than is needed, and therefore alerts to the potential risk of overdose/misuse of medication, there is no system in place to alert GPs when patients, particularly those with vulnerabilities, do not order their repeat medication.

First introduced in 2009, Electronic Repeat Dispensing (eRD) is a method of dispensing prescriptions electronically. Using eRD, GPs can issue up to 12 months’ worth of regular prescriptions so they are ready at the pharmacy each time a patient needs them. The new GP surgery informed the review that whilst care homes do not appear to use this system, it would have been beneficial in this case to prevent the cessation of medication. However, the review panel advised that it is possible that the eRD is not widely known about and there needs to be awareness raising amongst social care accommodation providers.

The ICB and health partners in Sunderland are currently working on proxy access to records in terms of medication that is focused on all older person’s care homes, this could then be extended to learning disability care homes, and that the wider system that needs to support and take a lead on this.[6]

Understanding the purpose of medications, side effects and consequences of missed doses and overdose

Swanton staff accepted the changes to James’s medication i.e. the discontinuation of Apixaban, Atorvastatin and Tamsulosin, and did not appear to demonstrate professional curiosity with regards to the consequences of these medications being stopped.

The review has questioned to what extent care providers and their staff understand the medication prescribed to the people they support i.e. what the medication is prescribed for,

[6] https://www.england.nhs.uk/ourwork/clinical-policy/proxy-access-to-gp-online-services-by-care-home-staff-guidance-for-care-homes-and-gp-practices/how-proxy-access-works/

the effects of a missed dose, reduction or increase in dose or sudden cessation, the side effects of medication and when to seek medical assistance.

Recommendations

1. There should be guidance for the different professionals around transition planning for when a person moves from one placement to another. Any guidance should be specific to the role each professional/agency plays in the transition process.

2. The above guidance should include the process for transferring information about an individual who is moving from one local authority area to another.

3. Transition plans must include plans for ongoing health support and medication, with assurances of continuity and sufficient supplies of medication whilst transferring GPs, and providing a contingency in the event of delays acquiring medication from the new practice/pharmacy.

4. Transitions plans should be multi-disciplinary with clarity around the roles, responsibilities and expectations of the professionals supporting the individual.

5. Social care accommodation providers to ensure that individuals who have moved to their provision are registered with a new GP on the day they move (or on next working day) to minimise the risk of interruptions to the continuity of healthcare provision.

6. Patient summaries should always include a list of prescribed medication and should reflect the 'state of play' from the day before registration ended.

7. GP surgeries should be notified in advance when a vulnerable patient with complex needs will be moving to their practice, and to be encouraged to engage in the transition process.

8. GP surgeries to consider gathering information in relation to vulnerabilities at point of registration.

9. Professionals should have a clear understanding of the roles of psychiatry and general practice, and that the GP is the prescriber of medication.

10. The lead partner/commissioner should be clear with everyone involved about how to escalate concerns, and who to contact to seek resolution to issues with prescribing. Social care accommodation providers should seek further clarity from the lead partner/commissioner about this when issues arise.

11. Psychiatrists should be explicit in correspondence to patients and other professionals that the list of medications included in any correspondence may not reflect the full list of medication prescribed.

12. Psychiatrists should be aware of all medication prescribed by using the GNCR (including that for physical health) in case of contraindications.

13. Social care providers must verify any apparent changes to medication through formal written communication from the prescriber.

14. GP practices to consider a system for alerting GPs when repeat medication for vulnerable patients is not ordered or collected.

15. Raise the profile of Electronic Repeat Dispensing amongst social care accommodation providers

16. Social care accommodation providers to consider the use of Electronic Repeat Dispensing.

17. Consideration to be given to proxy access to medical records for learning disability care homes.

18. Care providers should ensure that each client's care plan contains a list of prescribed medications which details what the medication is prescribed for, the effects of a missed dose, reduction or increase in dose or sudden cessation, the side effects of medication and when to seek medical assistance.

19. For the ICB to consider the totality of the recommendations made by this review, share with the Learning Disability GP lead and Safeguarding GP lead to consider the findings and recommendations, and report on how the learning and recommendations will be implemented/communicated out through primary care.