Cambridgeshire and Peterborough Safeguarding Adult Partnership Board

Case Review ‘Mark’

Date: December 2022

Contents

Introduction

This review focuses on Mark, a 50-year-old man, who died in 2019 at the care home in which he was accommodated.

In December 2019, following the death of Mark, a consultant psychiatrist from Cambridgeshire and Peterborough Foundation Trust (CPFT) completed a referral to the Adult Safeguarding Partnership Board’s Safeguarding Adult Review (SAR) sub-committee for consideration of the completion of a Multi-Agency Review (MAR). Safeguarding partners were requested to provide relevant information and the case was considered by the SAR subcommittee in September 2020.

When all of the information was obtained the decision by partners was that the case did not meet the criteria for a statutory Safeguarding Adult Review. However, it was felt that a Multi-Agency Review of the case could provide some learning for both those agencies involved with Mark before his death and wider safeguarding partners. This review was commissioned under Section 44(4) of the Care Act 2014.

Methodology

The SAR sub-committee formulated terms of reference for the review. It was agreed that the review should cover the period 1st July 2017 to 26th November 2019 and the following areas would be considered:

- How was Mark’s mental capacity assessed and what effect did this have on the medical treatment he received?
- How effective was communication between the agencies involved in Mark’s care?
- How was the Deprivation of Liberty Safeguard used in the care of Mark and how did this link to considerations regarding his mental capacity?
- Was there a link between Mark’s medication regime and his medical condition and if so, was this reviewed and the implications considered?
- Are there any areas of good practice?

The review also sought to identify any early learning from the review and whether there had already been organisational remedial action taken or whether the issue remained unresolved. The review also considered if the principles of Making Safeguarding Personal (MSP) were applied when professionals worked with Mark.

Reviews should be proportionate to the complexity and nature of the particular case. In this case the SAR sub-committee decided that a proportionate and strength-based review, using chronologies and a facilitated agency meeting to draw out the good practice and areas for learning would be used.

A facilitated multi-agency event was held in May 2021, with agency representation from the Clinical Commissioning Group (CCG), hospital, care home and CPFT. Additional information had been received via emails from another local authority and their NHS Trust and Hertfordshire Urgent Care (HUC).

Background of Mark

During his adolescent years Mark was hit with a cricket bat, whilst playing cricket, that led to brain injury. Mark had suffered from mental health difficulties for most of his life and was diagnosed as having Hebephrenic Schizophrenia. According to CPFT, disorganised or hebephrenic schizophrenia describes a person with schizophrenia who has symptoms including:

- disorganised thinking
- unusual speech patterns
- flat affect
- emotions that don't fit the situation
- incongruent facial reactions
- difficulty performing daily activities

CPFT have confirmed that an individual with schizophrenia who is described as hebephrenic does not have hallucinations or delusions but instead has disorganized behaviour and speech.

His first admission to mental health services was in 1987. He was detained under Section 3 of the Mental Health Act 1983 from June 1993 until his Community Treatment Order began in December 2009. There is no further information available, in relation to his mental health prior to 2009, once he had been moved to the Cambridgeshire area. Mark was placed in a care home in Cambridgeshire by another local authority's NHS Trust. He continued to have support from the care coordinators/ social workers, from this authority throughout the timeline of this review. According to the other local authority's NHS Trust, Mark's S.117 status arose because he had been an inpatient with them under Section 3 of the Mental Health Act (MHA) 1983 and was subsequently eligible for S.117 aftercare. That local authority area therefore remained responsible for overseeing and reviewing Mark's aftercare under S.117. This function was delegated to the health trust under a S.75 agreement (NHS Act 2006). As Mark was living in Cambridgeshire, responsibility for his mental health care needs fell to the local mental health services of CPFT.

He was accommodated in a care home in Cambridgeshire on 24 November 2009 and had a Deprivation of Liberty Safeguard (DoLS) in place that was undertaken by the other local authority in 2009. According to an email sent from the other local authority's DoLs team, the most recent DoLs for Mark was recorded as being in place from December 2018 and the following conditions were stated (i) Managing Authority to arrange a medication review of Mark's Medication (ii) Mark is prescribed Clonazepam and this requires the Managing Authority to arrange a mental capacity assessment (MCA) for the administration of Clonazepam and a Best Interest Assessment decision to be completed. In this instance the DoLs team confirmed that the 'managing local authority' refers to Mark's care home and that they were the supervisory body who issued the standard authorisation of the DoLs. An MCA was undertaken by the care home in August 2018 with regards to ascertaining if Mark had the capacity to refuse taking laxatives and if he understood about the medications that he was prescribed. The care home report that they have been unable to locate any copies or records of Mark's Best Interests Assessments. Therefore, no findings can be made about Best Interests Assessments that may have been undertaken by the care home for Mark.

The care home described Mark as a complex man who liked to dress so that he looked smart. Although he did have the capacity to choose what to wear, he would not have the capacity to enable him to cross the road safely. There were times when Mark did not want to be examined and he was described by health and care home colleagues that he could use 'colourful language’ when he did not want to be examined. Given his medical condition, he was also unable to wait patiently for lengthy periods of time.

Mark had been prescribed Clozapine over a long duration and this was monitored through the Clozapine review clinic. Due to his medication, Mark suffered from severe constipation and acute abdominal issues and as a result was prescribed strong laxatives.

Mark was taken to hospital by his carers, during November 2019, but treatment was challenging due to a lack of cooperation from him, mainly due to his mental health.

On the 14 November 2019, Mark was referred to the hospital by his General Practitioner (GP), with chronic constipation and to “admit him to surgeons”. After attending hospital and waiting for over two and half hours Mark absented himself without being seen and receiving care. On the 15 November 2019 the care home contacted the safeguarding team at the hospital and requested reasonable adjustments for Mark given his medical condition. Mark was returned to hospital the following day and hospital records state that he was discharged after over an hour and a quarter however, there was no recording of what basis Mark was discharged on. On 19 November 2019 Mark was again admitted to hospital and after initially refusing to be examined he did comply with the consultant and after six hours was discharged. Mark was given a treatment plan to take picolax (laxative) and to be referred by his psychiatrist to a tertiary hospital specialist for further management in the long term.

On the 20 November 2019 HUC was contacted in relation to Mark’s extended abdomen and constipation. Mark was reviewed via telephone contact and the call was closed with no further action needed with records indicating that Mark had constipation. The care home contacted the out of hours doctor on 23 November 2019 at the request of Mark due to his constipation and their concerns that he did not look well. GP records indicate that this was not a new issue and that the vital signs given by the care home were slightly high but not worrying. Mark was seen by the out of hours doctor early in the morning of the 24 November 2019. The staff at the care home were asked by the out of hours GP to observe Mark and liaise with GP on a long-term plan. On 26 November 2019 Mark died, and the cause of death was given as Bronchopneumonia, Ileus and Paralytical Megacolon noting a Clozapine effect.

Summary of Agency Involvement

Throughout the timeline under consideration, it is recorded that Mark was prescribed various medications by his GP on a monthly basis which included, anti-psychotic and anxiety drugs, epileptic medicine, sleeping tablets and anti-sickness medication. A reported side effect of many of these prescribed drugs is constipation and to help counteract this Mark was also prescribed a combination of laxatives. Blood tests were undertaken each month to monitor and review Mark’s blood works and electrocardiograms were initiated to check for any ECG anomalies due to being prescribed anti-psychotic medication.

2017

In June 2017 it was noted on the GP records that Mark did not attend the GP surgery for his annual health check. A couple of hours later, that day, he was visited at the care home by the specialist nurse practitioner and although Mark declined his health check it is recorded that he had some ‘abdo [abdominal] discomfort’. The specialist nurse continued to visit Mark at the care home on several occasions throughout the timeline.

August 2017 is the first recording, in this timeline, for the request from care home staff for an enema due to Mark’s ‘chronic constipation’. At that time the enema was not prescribed as it was considered that the laxatives should be sufficient. There was a further record of an enema being given in November of this year.

In October 2017 Mark 'declined' to have a seasonal influenza injection that was offered to him by the GP surgery.

On 31 December 2017, 111 was contacted by the care home as Mark felt unwell and was limping. A doctor from Hertfordshire Urgent Care (HUC- emergency out of hours doctor) examined Mark and diagnosed the formation of an abscess on his inner left thigh and he was given medication and advised to see his GP.

2018

On the 3 January 2018 the care of Mark, in relation to taking Clozapine, was transferred to CPFT from a Social Worker in the other local authority health trust.

According to the other local authority's social care the DoLs was a standard DoLs and was granted on 12 January 2018. There are no records from the care home as to whether a meeting with Mark with his social worker/ care coordinator or a representative from the DoLs team took place in relation to this.

On 4 January 2018, the specialist nurse saw Mark at the doctor's surgery, to review the abscess. Whilst at the surgery he was seen by the smoking cessation advisor, and it is recorded that 'cessation advice' was given to Mark. On 11 January 2018 the abscess was noted, on the GP records, to be 'improving'.

On the 8 January 2018, Mark was seen by a CPFT psychiatrist, and a core assessment was undertaken. This recorded that Mark was compliant with his medication but that he was 'overactive and getting into people's spaces'. It was also noted that he had 'severe constipation' but otherwise had no other physical health issues. The care home recorded that Mark would be seen annually by a psychiatrist and monthly at the Clozapine clinic. Mark attended his next Clozapine clinic appointment on 9 January 2018.

A safeguarding referral dated 20 December 2017 made by CPFT was uploaded onto CPFT recording systems on 20 January 2018 where Mark had been assaulted by another resident and it was noted on 23 January 2018 that, in response, the care home had put safeguards in place.

Mark's care coordinator, from the other local authorities NHS Trust, held a section 117 care review, in April 2018, with Mark and his carers. The care plan supplied by the care home shows that 'Mark shows considerable risk around his medication compliance' and is a risk to himself and others whilst in the community. The care plan indicates that Mark needed full support with his daily living skills, 24hour nursing care to support his mental health and medication compliance and that he should remain on DoLs due to being at high risk within the community. The documentation also notes that prior to being accommodated in the care home Mark was an inpatient for 10 years but does not state which establishment.

It was noted on GP records, that in March 2018 Mark had a burn to his foot which was dressed by the nurse at the GP surgery and in May 2018 Mark had an injury to his toe which was attended to. In June 2018 HUC was contacted by the care home as Mark had a swollen and pain full knee. Mark was seen by HUC, and records note about the knee and that Mark had 'chronic constipation'.

In July 2018 a psychiatrist recorded in a medical review that Mark's mood had stabilised over the past few months, that he was reluctant to take his enemas and that one of the drugs he was taking would be gradually reduced.

An MCA was undertaken by the care home in August 2018 and concluded that Mark lacked capacity in being able to refuse to take his laxatives and in understanding about his prescribed medications. Despite repeated requests, to the care home, no further information has been provided in relation to any Best Interests Assessment being undertaken for Mark.

On 29 August 2018 CPFT recorded that a MASH (Multi-Agency Safeguarding Hub) referral had been uploaded with reference to 'a low-level physical assault' on Mark by another resident. The care home confirmed that this was not the same resident that attacked Mark in December 2017. CPFT records stated that the incident was 'dealt with by staff'. There are no further records either on CPFT files or care home records to indicate what the 'staff' did to safeguard Mark in this instance nor how the assault was addressed.

On the 11 October 2018 it is recorded on GP notes that Mark 'declined' to have a seasonal influenza vaccination that was offered to him by the GP surgery.

In November 2018 Mark was seen by the continence service who advised using pads along with fluid management and dietary changes. It is also recorded that Mark had had a sigmoidoscopy but that no treatment could be given due to 'cooperation issues'. During November 2018 Mark also successfully attended the clozapine clinic.

During 2018, the care home noted the increasing usage of enemas for Mark and that sometimes he was refusing to take them. This was also noted on his S117 care plan back in April 2018. Staff, at the care home tried to 'persevere' with Mark in relation to him taking the enemas and advised the GP of his refusal. The care home recorded on one occasion that Mark needed help with personal care and access to incontinent pads as a result of his bowels opening. As previously mentioned, the mental capacity assessment undertaken by the care home showed that Mark lacked capacity to understand about taking his medication and surrounding taking or not taking his laxatives.

Towards the end of 2018, CPFT released an urgent warning to health care professionals in relation to patients on a high dosage of Clozapine. The alert stated that 'Heatwave conditions may significantly increase risk of constipation/exacerbate existing constipation in patients on high dose Clozapine. Risk of adverse effects may be increased further where the patient is a smoker'. On discussion with a representative from CPFT, a point to note here is that a patient taking Clozapine and who smokes will experience a reduced effect of the Clozapine.

2019

On 31 January 2019, Mark attended the GP surgery and records showed that he was seen by the smoking cessation advisor and that he refused 'to stop smoking'. Records indicate that cessation advice was given and that this would be monitored.

During January 2019, Mark was prescribed an enema and during February 2019 there were 5 reported incidents by the care home where Mark had been incontinent and needed support to have baths, showers and to change his clothes. Constipation, the use of enemas and continence issues continued to escalate through the year.

In February 2019, CPFT contacted the care home as the doctor wanted to discuss Mark's Mental Capacity Assessment and Best Interests at a review to take place in March 2019. There is no evidence to suggest that the DoLs was not complied with, however this does raise concerns in relation to the recording of agencies.

The psychiatrist, on 14 March 2019, noted that Mark was 'compliant' with his medication which caused 'constipation' and believed that 'all organic issues' for the constipation had been 'ruled out'. It was requested that the GP undertake 'blood tests' and make a referral to 'gastro' due to Mark's 'bloated abdo' [abdominal region]. The GP records show that the blood tests requested by the psychiatrist were 'postponed' but no reason was recorded as to why. Further recording on the GP files noted that Mark had been 'investigated in the past' and that the request from the psychiatrist will be reviewed 'after bloods'.

On 15 March 2019, the psychiatrist phoned the care home to advise that one of Mark's medicines had been replaced in 'response to the DoLs condition' and that if Mark relapsed, he should be taken to hospital to have his medication reviewed.

GP records indicate, on 19 March 2019, that Mark's blood tests were 'reviewed' and recorded as 'normal' with 'no further action'. There are no further details recorded as to whether a referral to 'gastro' requested by the psychiatrist was made by the GP nor if the blood test reviewed by the GP on 19 March 2019 were the one's requested by the psychiatrist earlier in the month.

On 25 March 2019, the care home had a telephone consultation with the GP in relation to Mark having a 'red eye'. Later in the month, care home records indicate that Mark seemed confused saying that he had 'died' and in response the staff went to reassure him.

According to care home records, in March 2019, an advocate went to see Mark, at the care home, to explain his medication to him. The care home records did not record which advocacy service was used nor if this was a specialist Independent Mental Capacity Advocate (IMCA). The care home report that they paid for an approved inhouse IMCA from an independent advocacy organisation to support Mark in understanding about his medication. It is not possible to ascertain any further information as the advocacy service who was reportedly involved as Mark's IMCA have no records in relation to Mark.

Mark's Care Coordinator from the other local authority's NHS Trust held a section 117 care review, in April 2019, with Mark and his carers. Care home records indicate that the social worker [Care Coordinator] made reference to his care plan, nursing needs, continence, and epilepsy. The home noted that Mark was unsettled throughout but did consent to the review. There is no evidence from either the care home records, nor the section 117 review that an Independent Advocate was present to support Mark during this review. The section 117 review, undertaken by the specialist psychosis team of the other NHS Trust, noted Mark's increasing 'absence seizures' (epilepsy) and a request for the GP to review Mark to consider the 'combined risk of continuing clozapine and having seizures'. There are no records as to whether the GP received the section 117 review's requests nor whether the request was acted upon. The review referred to a number of 'safeguarding concerns' in relation to Mark's sexualised behaviour and comments towards women, his risk of absconding and due to his increased need for cigarettes the risks associated with him 'barging people' out of the way or being manipulated by other residents. The review notes that staff at the care home worked one to one with Mark on these issues and supported his daily living and financial skills. There was a section within the review that stated that 'there does not appear to be any identifiable precipitating factors' to Mark's constipation, faecal incontinence, and epilepsy.

On 25 April 2019, psychiatrist records indicate that Mark was severely agitated and had insomnia and requested that staff (though does not state which staff or from what agency) make a referral for an Independent Mental Capacity Advocate (IMCA) and for his medication to be adjusted. There is no recording on CPFT or care home files if an IMCA was requested or if an IMCA attended to support Mark's understanding about his medication and the proposed changes to be made to his medicines.

Both GP and CPFT records show that on 25 April 2019, the psychiatrist noted that the Clonazepam had been tapered and stopped by March 2019. Clonazepam was the only named medication referred to within Mark's DoLs.

The psychiatrist noted, in May 2019, that there had been contact from the care home, as Mark had hit several residents over the past few days. The psychiatrist recommended that the carers sit down with Mark and talk to him about his behaviour, start an ABC plan (antecedents, behaviour and consequences) and also to test Mark for a possible urine infection. The care home reported that staff sat down with Mark and went through the ABC with him and that a urine test was undertaken that later showed 'no anomalies'.

The care home's dietician saw Mark in May 2019, and records state that Mark had not been to the toilet for 12 days but that he did not complain of any discomfort and continued to eat well. On 19 June 2019 the dietician, requested a scan of Mark's abdomen.

According to care home files, Mark was seen in June 2019 by the social worker [care-coordinator] from the other local authorities NHS Trust, who went through Mark's care plan with him.

On the 10 June 2019 the psychiatrist visited the care home and noted that Mark was 'stable with reduced behavioural issues' but had' worsening health due to constipation' and that the plan was to 'consider reducing Clozapine'. According to the psychiatrist's records on the 10 June 2019 at a review meeting within the home, the care home stated that a referral for an IMCA had been made. There is no further information available as to whether Mark was seen by an IMCA.

On 24 June 2019 the care home contacted the psychiatrist to say that Mark was showing aggression towards staff and residents and that he was touching people inappropriately.

On the 24 July 2019, GP records note that an 'ultrasound form was sent'. The GP visited the care home on 23 August 2019 as Mark was constipated and experiencing cramps but after examination the GP felt that there was no indication of bowel obstruction.

Psychiatrist records show that Mark was reviewed monthly at the clozapine clinic from August 2019 to November 2019.

Carers took Mark to hospital on 9 September 2019 for his ultrasound appointment on his abdomen. The ultra-sound upper abdomen report noted that the results of the scan were 'abnormal' and that the GP should review the findings and Mark to be given a routine follow up appointment. Two GPs reviewed the findings along with further test results and no further actions were recorded.

During October 2019, Mark was visited at the home by his advocate. Care home records state that Mark 'engaged with the advocate'. On speaking to the advocacy services involved with Mark's case, the advocates attended the care home as a Relevant Person's Representative (RPR). The RPR's visited the care home on a monthly basis to ascertain whether Mark was objecting to his deprivation of liberty. Both services reported that Mark did not challenge his DoLs and one advocate stated that although Mark felt restricted at not being let out on his own he was settled in his care home and felt safe. Neither service, in this role, discussed Mark's medication or his understanding of it, they stated that this would be a matter for a different type of advocacy support.

On 12 November 2019, the care home contacted the GP to request further enemas for Mark. By the following day Mark's blood pressure was raised and he was observed to be breathless. On 14 November 2019, Mark was taken into ambulatory care, after being referred by his GP. The care home records note that the GP wrote a letter to the hospital that they believed stated that 'Mark lacked capacity to make decisions regarding his medical care'. The GP records indicate a consultation where Mark was diagnosed with chronic constipation and to admit to surgeons, however, there was no record in relation to a letter referring to Mark's mental capacity. The care home's records noted that Mark was 'impacted' and 'would need manual evacuation'. Once at hospital Mark initially refused to have a blood test and then after coaxing from his carers he agreed. However, after waiting some time Mark became verbally abusive and left the hospital without having the blood test or receiving any treatment. The care home later contacted the hospital to try to support Mark's health needs by explaining that due to his mental health conditions Mark struggled with waiting for lengthy periods of time.

On the advice of the GP and nurse on the 16 November 2019, Mark was taken by carers to the accident and emergency department, with constipation and abdominal pain. On arrival at the hospital Mark refused to give bloods and as a result could not undergo treatment [manual evacuation]. He was discharged from the hospital with an 'optimised laxative regime'.

On 19 November 2019, Mark's new psychiatrist referred Mark back to the hospital, with abdominal pain and a grossly distended abdomen noting that his concern was of 'perforation' [of the bowel] and he added that Mark had 'no capacity'. The psychiatrist requested that the hospital section Mark as this situation was in relation to Mark's physical health and the risk of fatality. During his short stay in hospital Mark was observed to be abusive, refusing to be examined and then becoming co-operative. The hospital noted that Mark having enemas was 'futile' as his rectum was empty and that he should be referred by his psychiatrist to 'tertiary specialist hospital in the long term' and Mark was discharged.

On the 19 November 2019 the psychiatrist agreed with the care home that Mark's Clozapine intake was to be gradually reduced and that he would advise the pharmacy.

Over the next few days HUC was contacted by the care home and Mark was seen at the care home by an out of hours GP in relation to his constipation and feeling unwell.

On 26 November 2019, Mark started to have trouble breathing, at the care home and asked to see his 'mum and dad'. Mark lay down in his room and staff tried to help him with personal care by changing his soiled clothes. Mark stopped breathing and his carers called 999 and administered CPR (cardiopulmonary resuscitation) with support from the ambulance service over the phone. The air ambulance, doctor and paramedic arrived and continued with CPR for approximately 20 minutes after which Mark was pronounced dead.

Analysis

The analysis of the answers to the questions set in the terms of reference comes from the information contained within the initial SAR referral form, agencies chronologies, contact with agencies and the agencies recollections and reflections from the facilitated multi-agency event.

In order to ensure continuity and context, the 'good practice' in Mark's case from agencies has been included within each section as have the references made to MSP. Additionally, the learning points from the review have been highlighted in italics for easy of reading and understanding.

How was Mark's mental capacity assessed and what effect did this have on the medical treatment he received?

It was clear from the facilitated multi-agency event that, some agencies were aware that Mark was subjected to a DoLs and that some agencies were not. With the exception of the care home none of the agencies who were treating Mark were aware of what was written within the DoLs. *It may have been helpful to know what was written within the DoLs to support Mark in his care and treatment and to guide and support further assessments and reviews.*

The care home was required to complete an MCA and Best Interest Assessment as part of the requirements of the DoLs, that was supervised by another local authority. The care home initiated an MCA in August 2018 in relation to ascertaining if Mark's had capacity to refuse taking his laxatives and if he understood what his prescribed medicines were for and what would happen if he did not take them. The mental capacity assessment concluded that Mark 'lacked capacity' in both these areas. However, this information was not shared with all the health agencies working with Mark. The care home felt that the MCA was their assessment in relation to Mark in the care home and that unless access to the MCA was requested by an agency then this would not be shared. This is unfortunate as agencies would not necessarily know about an MCA having been undertaken unless they were informed. By having an MCA and a Best Interests Assessment this indicates that there are capacity issues for the individual in being able to understand certain issues and to make decisions. Sharing the fact that Mark had an MCA would have flagged up to other agencies working with Mark about Mark having capacity issues. Additionally, in Mark's case *any MCA undertaken by any agency would have helped inform other partner agency assessments and potentially Mark's treatment.*

From the medical records, it would seem that Mark had some capacity around particular issues for example refusing vaccinations and continuing to smoke even though he had been to several smoking cessation clinics. However, in terms of his treatment and GP attendance there was no evidence of capacity assessments or Best Interests' assessments taking place. These *assessments would have informed the GP surgery, clinic and psychiatrists about Mark's capacity and if it was ascertained that he lacked capacity, then would advise what would be the best interests for him in terms of treatment*.

On contacting the care home after the facilitated multi-agency event they confirmed that due to Mark's mental health condition staff escorted him to hospital as they were aware of the possibility that Mark could leave before undergoing any examinations and treatment. The care home also stated that the hospital passport which Mark carried with him stated that he was the subject of a Dols. However, the hospital passport documentation supplied by the care home makes no reference to a DoLs, MCA or a Best Interests assessment for Mark. Although, at the facilitated multi-agency event the care home confirmed that staff attending the hospital with Mark would inform the hospital staff that Mark suffered from mental health issues and had a DoLs in place.

When Mark was in attendance at the hospital, given his medical condition, he was unable to wait for lengthy periods of time and he also became abusive towards staff making examinations and treatment difficult. In this instance it would have been advisable to have an MCA assessment and Best Interests decision undertaken whilst in hospital in relation to the impact of the diagnosis and treatment for Mark on the physical health issues he was presenting with. During the several admissions into hospital an MCA assessment was not undertaken by the hospital *which may have advised medical staff about Mark's capacity to remain in hospital as well as supporting his treatment needs*.

In Mark's case, with the exception of the care home who completed MCA assessments, in relation to specific treatment for physical health needs and support no MCA assessments or Best Interests decisions were undertaken by the GP or the hospital. *These were missed opportunities for supporting Mark's chronic and acute health needs for when he was constipated and then later when he needed emergency treatment.*

At the facilitated multi-agency event, it was noted that there appeared to be confusion with regards to communication between the psychiatrist and the hospital in relation to what legislation Mark needed to be detained under for hospital treatment. According to hospital records the psychiatrist advised the hospital that he was concerned about perforation [of the bowel] and that Mark could be 'sectioned' as he lacked capacity to make a decision about physical health and added that this [situation] was not about mental health. The psychiatrist notes also reported that the hospital was advised to 'hold him and treat him under the Capacity Act'.

On discussion at the multi-agency event, it was felt by partners that, even if Mark was sectioned, physically restrained or sedated under the Mental Health Act 2005 in order to undergo treatment, then such actions would not necessarily have been in Mark's best interests at the time and may have made the situation far worse.

It was good practice, that in terms of Mark's general physical health he was attended to on a timely basis and when he injured himself medical records show that he was given appropriate medical treatment.

How effective was communication between the agencies involved in Mark's care?

Partners felt that the communication between members at the Clozapine clinic was good as was the continued contact and support from the clinic with the staff at Mark's care home. The care home effectively communicated with agencies and asked for changes in the way Mark was treated, in order to accommodate his needs whilst at the same time enabling Mark to agree to and allow the treatment. An illustration of this was where the care home arranged with agencies, to take Mark's blood in a morning when Mark was' barely awake' and less likely to 'refuse' and then the blood vial would be delivered to the relevant agency for testing. This was instead of trying to get Mark to the relevant health agency for them to try to take his blood and for him to get upset and refuse. However, it is not recorded on agencies records whether an MCA assessment was considered or undertaken in relation to Mark's understanding surrounding having his bloods taken.

It was noted, at the multi-agency event, that the nurse from the GP practice had a good relationship with the care home and with Mark and visited many times to see him and to administer treatment.

It was highlighted as 'good practice' when the pharmacy refused to change Mark's drug regime without a GP's letter highlighting the changes. This prevented potentially incorrect amounts of medication being dispensed but also highlights that *when changes are made to medications for patients the pharmacy should be informed.*

It was good practice that Mark had an advocate who visited him at the care home to explain his DoLs and to ascertain if he was still happy to be at the care home. In terms of Making Safeguarding Personal, *where possible an advocate should be considered to support those people with care and support needs in their understanding and decision making*. According to care home records, there were several advocates who visited Mark to support him on different issues. However, the records were not clear as to which advocacy service was used and from what geographical area they came from and at times it was not recorded what the purpose of the advocate visiting Mark was. Additionally, the advocacy service's details given by the care home in relation to IMCA support have no written records of advocacy for Mark. Therefore, it is difficult to clarify with any certainty if Mark was fully supported by advocates when required, particularly around understanding his medication nor if Mark's views and wishes were heard and considered.

The care home always made sure that Mark had his 'hospital passport' with him when going to hospital that contained useful information about his mental health history that was kept in a red packet. This was regarded at the multi-agency event as good practice, however the care home reported that Mark often did not return home with the passport and papers seemed to get lost. The hospital passport was completed during February and June of 2017 and the details of the social workers [care professionals] working with Mark had changed by 2019 when Mark was admitted to hospital. Additionally, the list of prescribed medicines listed on the hospital passport did not tally with what was written on Mark's medical files in terms of dosage and current medication. *It is important that documents such as hospital passports are kept up to date for informing health professionals about patients with complex social and health needs.*

None of the agencies were able to access each other's recording systems for sharing information given that access to electronic systems was precluded outside of certain organisations. Even though Mark had signed a consent agreement with the home for sharing his information, there would still be other permissions and confidential aspects to consider. That said the agencies at the learning event felt that *a type of multi-agency meeting, in Mark's case may have been helpful, to share information, given that he was a man with very complex issues and needs.* However, this type of multi-agency meeting should not be confused with the MARM (multi-agency risk management) process, as in this case given that Mark lacked capacity, he would not meet the criteria for undertaking a MARM.

Agencies discussed the possibility of a different referral pathway or processes for patients such as Mark to be put in place to accommodate their complex needs for gaining access to treatment at hospital when in crisis. However, it was acknowledged that this may prove difficult as this, would have to be developed on an individual needs basis, agreed at a senior levels in a variety of health organisations and implemented into practice in hospitals that are dealing with many other acute patients in emergency situations.

There were times, recorded within the chronology, when the care home contacted the GP and HUC with serious concerns about Mark's health deteriorating and in response the GP's gave telephone consultations and suggestions as to what to do to support Mark. The agencies at the facilitated multi-agency event felt that *these were missed opportunities for when Mark could have been physically examined that might have provided a different assessment of the situation and invoked an alternative response from the doctor*.

There is no recorded evidence that the GP was aware of Mark having a Dols nor of the GP knowing what was written in the Dols.

Limited information was provided by the care home, CPFT and the other local authority DoLs team as to who the social workers / care co-ordinators for Mark were or where they were located. After extensive inquiries as part of this SAR a mental health team within another local authority's NHS Trust was identified as the health and social care support for Mark. The section 117 undertaken by that NHS Trust also reflects that, other than references made to the care home very little information was recorded about the other agencies and teams working with Mark. This is a missed opportunity in terms of a working together to support Mark with his medical and social needs. *In terms of sharing information and contacting relevant services for support and working together agencies should record clearly what agencies are involved with the adult at risk, what their roles are and what their contact details such as an address, email and main line telephone number.*

Many of the agencies working with Mark appeared to work in isolation of one another and potentially missed the opportunities to share information that would have supported Mark's care and support needs. CPFT knew about the side effects of patients taking Clozapine and released urgent warnings in 2018 of the risks associated with the drug. The other local authority's NHS Trust reported escalating seizures for Mark and a possible link to taking Clozapine. However, it is not clear from agency records or reviews whether the agencies working with Mark were aware of these issues.

Not all the records of the agencies involved in Mark's case had clear descriptions of events and treatment with a rationale for the actions /activities recorded and of the outcomes. There were also instances where important information, documents and events were omitted from agencies records. For example, within the GP notes, it was not recorded whether missed appointments with Mark had been followed up by the practice nor why the GP had on one occasion changed Mark's medication. The care home records did not record all events for Mark and in some instances gave little description and details of what events did take place. For example, there are no records in relation to Mark being attacked by other residents nor evidence of safeguarding referrals made in relation to the attack and no recorded plan of action to address the assault and how to keep Mark safe. As a final illustration there are no completed Best Interests assessments for Mark undertaken by the care home recorded on file. *Making sure that events are recorded and that records are clear, concise, explanative, have a rationale and avoid jargon is essential not only in terms of recording events and concerns but also for sharing information and for overall accountability*. *Important documentation such as assessments, reviews and reports should be recorded and available on service users records to ensure that legal procedures are met to support and to safeguard the adult at risk.*

Agencies at the multi-agency facilitated event felt that they learned more about Mark and his complex and sometimes challenging behaviours, from the discussion amongst the agencies than what was recorded within any of the agency records. *For a person with care and support needs, with or without complex issues, having an overall 'pen picture of the person' would be beneficial for practitioners and agencies to tailor their practice to their needs and to make safeguarding personal.*

How was the Deprivation of Liberty Safeguard used in the care of Mark and how did this link to considerations regarding his mental capacity?

As previously noted within this report, Mark had a DoLs authorisation in place that was supervised by another local authority and was reviewed in 2018. However, few agencies knew about Mark having a DoLs nor had access to what was written in it.

The facilitated multi-agency event discussed that when a person is subjected to a DoLs, this would be in respect of the decisions made in relation to their care arrangements. Therefore, knowing about the contents of the initial DoLs supervised by another local authority would not have been useful in an emergency medical situation such as Mark's case.

One of the DoLs requirements for Mark was that the managing local authority (the care home) should complete Best Interests assessments for Mark. The supervisory authority stated that they do not hold files in relation to MCA's or Best Interests assessments and that this would be the responsibility of the care home as the managing authority. However, it is of great concern that the care home report to have no evidential records or copies of any Best Interests assessments on Mark's file that they state were undertaken. Therefore, at this time I am unable to clarify whether any Best Interests assessments were effectively undertaken by the care home to safeguard and support Mark.

There were changes made to Mark's medicine regime during March to April 2019 by CPFT and the GP where the Clonazepam had been tapered off and stopped. This was the only medication that Mark's DoLs referred to. The section 117 review undertaken by Mark's Care Coordinator from the other local authority's NHS Trust, at the care home, recorded that Mark was 'currently having his medications reviewed for the purpose of his DoLs'. There are no records as to whether the care home (the managing authority) had advised the supervisory body (other local authority) of these changes that would have impacted upon the current Dols that was in place for Mark.

Was there a link between Mark's medication regime and his medical condition and if so, was this reviewed and the implications considered?

The effects of Clozapine and the other medications that Mark was prescribed were known to have side effects such as constipation. In 2018 CPFT released an urgent information sheet that patients on a high dosage of Clozapine could have increased risk of constipation or exacerbated constipation issues during a heat wave and that the risk increased if the patient smoked. It is noted that Mark had chronic constipation as a result of the medication that he took, and he was a smoker. There was also an emphasis within the information sheet that in cases of acute abdominal pain there needed to be urgent assessment. In 2020 a research paper (E. Rose, S. Chen and C. Turrion et al, 2020) explored the causes of death in clozapine-treated patients in a catchment area over a 10 year period. The paper concluded that although death in patients taking Clozapine was low, a high clozapine dosage was a risk factor for unexpected death mainly from physical causes. The paper suggests that 'clinicians should monitor regularly for potential side effects and educate about symptoms for early identification' whilst regularly monitoring clozapine levels in the blood (E. Rose, S. Chen and C. Turrion et al, 2020: P6). This highlights the importance of the need for the constant review and monitoring of patients taking Clozapine and of agencies being fully aware of the side effects of taking the drug.

At the facilitated multi-agency event attendees outlined that it was good practice that professionals present at the event knew about and recorded the potential side effects of Mark taking Clozapine. In Mark's case he was on a laxative regime, was offered smoking cessation sessions, had regular blood tests, medication reviews and ECG's. Additionally, he was seen at the Clozapine clinic and there was good communication between the clinic and the care home.

There were records from the psychiatrist that there was consideration of reducing Mark's prescribed Clozapine during June 2019. It was good practice that the reduction of Clozapine was immediately put into action once the new psychiatrist became aware of the potential life-threatening issues for Mark due to severe constipation that could have resulted in the possibility of having a perforated bowel.

As Mark's chronic constipation worsened and his abdomen became distended referrals were made for an abdominal ultrasound, different laxatives and enemas were prescribed and he was seen by the incontinence services and by the care homes dietician. Dietary changes were also suggested for Mark along with an increased fluid intake which the care home implemented and Mark complied with. Unfortunately, due to Mark's mental health issues this made it difficult for health professionals to examine him at certain times and for any surgical procedures to take place to evacuate his bowels. However, no MCA assessment or Best Interests assessment to support the treatment of Mark were undertaken at this time.

Whether Mark was in pain or not was discussed at the facilitated multi-agency event. The signs, to agencies working with Mark, were that he did not say that he was in any pain and that he continued to eat normally. However, health agencies at the meeting felt that given Mark's medical condition of a distended abdomen and a potentially perforated bowel he would have been in pain. *In terms of the 'lived experience of the adult' and making safeguarding personal it was suggested that professionals should think about wider observations surrounding an adult at risk and to note any changes in behaviours that are unusual for them. Additionally, professionals should consider using other methods of communication (work sheets / smiley faces / games) to understand exactly how a person with complex needs and capacity issues might be feeling*.

Recommendations

At the facilitated multi-agency event, agencies highlighted and agreed on a number of recommendations to be carried forward as part of the learning from Mark's case. This is with a view to help support any future cases and situations that maybe similar to Mark's.

1. Mark's case highlights the seriousness of chronic constipation and of the difficulties of working with adults at risk who are either reluctant or are unable to accept both the treatment for chronic constipation and having surgical evacuations for impacted bowels. Since COVID 19, it has been recorded that, there have been increased cases of people, who have learning difficulties, suffering extreme constipation during lock down and in the worst-case scenarios having perforated bowels. The NHS has prepared informative leaflets for both professionals and people with learning difficulties (easy read leaflets) to explain about constipation, how to avoid being constipated and what to do if people are constipated.

   - **This information should be available on the safeguarding boards website and be sent out to all care providers. This is to: (i) promote awareness about the seriousness of constipation (ii) show what support can be given to avoid constipation and (iii) suggest what to do when dealing with constipation. Such advice is useful for everyone and not just those people with learning difficulties.**

2. It was raised through the facilitated multi-agency event that medical assessments undertaken by telephone is extremely limiting and is a missed opportunity for diagnosing potentially serious health conditions. It was felt that Mark had experienced chronic constipation for so long that the GPs involved may have considered the calls from the care home to be a continuation of chronic constipation symptoms, when in fact Mark was seriously ill. Health agencies often referred to this as 'Diagnostic overshadowing'.

   - **Professionals, where possible, should consider undertaking assessments in the presence of the person concerned to provide opportunities to examine, observe**

and ask the individual about their experiences and feelings. Improved assessments effectively identify risk issues and offer the best interventions available for that person.

3. When a person is deemed to have 'capacity issues', agencies should consider undertaking a 'Mental Capacity Act assessment' and if necessary, a 'Best Interests' assessment'. In Mark's case this would have been beneficial for Mark's treatment across health agencies to support both diagnosis and treatment.

    - **Agencies should consider undertaking a 'Mental Capacity Act assessment' and if necessary, a 'Best Interests' assessment' when it is believed that a person lacks capacity.**

4. At the facilitated multi-agency event, participants all felt that having a 'pen picture' of Mark would have helped diagnosis, treatment and support for him.

    - **Agencies who work with adults at risk who have complex needs should consider noting, in a prominent place, on their records about the lived experience of the adult and what the individual behaviours and issues are for them.**

5. To ensure that adults at risk with complex needs are examined in hospital in as quick a time as possible, for their individual needs to be accommodated and for them to be able to understand and accept treatment given to them:

    - **A&E departments across Cambridgeshire & Peterborough need to review their current policies and procedures to ensure they are meeting their equality duty for adults with complex needs and behaviours when presenting in crisis, to ensure an appropriate pathway is enabled to meet their needs including reasonable adjustments where appropriate, to ensure urgent care access is available when required.**

6. Having a hospital passport for a person with care and support needs was identified by partners as good practice in Mark's case. However, for the hospital passport to be informative and useful to hospital and medical staff, it needs to be kept up to date and regularly reviewed by carers and to have the relevant important information about the individual contained within it.

    - **The safeguarding partnership to consider designing a hospital passport for use in all the hospitals across the Peterborough and Cambridgeshire region *and***
    - **For the passport to include an area for the contact details and roles of the professionals working with the adult at risk *and***
    - **For the local hospital passport to have a tick box set of questions as to whether the individual has: (i) a DoLs in place (ii) a Court Order of Protection in place (iii) a lasting power of attorney (for welfare) in place (taken from best practice observed in out of county hospital passports)**

7. When undertaking assessments, safeguarding enquiries and support plans with an adult at risk professionals **should always consider the use of an advocate**. If a person is deemed to lack capacity or maybe the subject of a Dol's a different type of approved independent advocacy service should be considered for supporting the adult at risk.

- **For agencies to make clear to their workforce about when to consider the use of an advocate and what type of advocate to contemplate utilising**
- **For the safeguarding partnership to outline the use of advocates and the different types of advocacy services within multi-agency safeguarding policies and multi-agency safeguarding training**

8. Accurate, succinct and timely recording of events is essential for safeguarding adults at risk. This is to provide accountability, evidence and a log of past, present and future records for assessing, planning and sharing information. It is also important to record what is meant by notes written, why decisions have been made and to avoid jargon and acronyms. It was noted that in Mark's case the care homes records were extremely limited and missing important information and assessments that would have helped to safeguard Mark and provide the best care for him.

    - **For the care home to review their record keeping procedures and to keep all assessments and records of events on service user's individual files.**

    - **For all professionals to make accurate, timely, succinct records of all events in relation to service users on their data bases.**

    - **For managers to have regular oversight and 'sign off' of practitioner's records as part of single agency monitoring / auditing and within supervision (where held).**

References

E. Rose, S. Chen and C. Turrion et al.,(2020). Causes of death in clozapine-treated patients in a catchment area: a 10-year retrospective case-control study, European Neuropsychopharmacology, https://doi.org/10.1016/j.euroneuro.2020.05.011