City of York
Safeguarding Adult Review
Catherine
March 2025

Contents

1. Introduction

1.1 This Safeguarding Adult Review (SAR) has been commissioned in respect of Catherine, a 79-year-old female with complex health needs, who sadly died on the 9th July 2020. The City of York Safeguarding Adults Board (SAB) commissioned this SAR in accordance with Section 44 of the Care Act (2014).

1.2 The Care Act 2014, Section 44, [1] requires that a SAB arrange a SAR when certain criteria are met. These are:

- When an adult has died and abuse or neglect has been a contributory factor, or has not died but has 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.

1.3 The aim of this review is to enable agencies to reflect and learn lessons about the way they worked both individually and collectively, to safeguard Catherine. This SAR will not seek to apportion blame to any individual or agency, or re-investigate, rather the focus will be on identifying learning in a transparent way, so that actions can be identified and collaboratively taken forward.

[1] https://www.legislation.gov.uk/ukpga/2014/23/section/44/enacted

1.4 The methodology chosen for this review is a multi-agency combined chronology overseen by an Independent Reviewer, starting with a tabletop review.

2. Terms of Reference

The terms of reference for the review were agreed as follows:

2.1 Utilising the overarching six principles of Adult Safeguarding[2] and the key principle of Making Safeguarding Personal establish whether there are lessons to be learned about the way in which professionals, agencies and any other relevant persons worked together to safeguard Catherine.

2.2 Review procedural effectiveness at both a multi-agency and individual organisational level with specific focus on Catherine's individual care journey to inform and improve local interagency practice and commissioning arrangements.

2.3 Evidence whether consideration has been given to any of the nine protected characteristics applicable to Catherine under the Equality Act 2010 in evaluating the agencies involvement with Catherine and whether she experienced any discrimination in employment, provision of goods and services and access to services such as education and health.

2.4 Undertake a critical review and analysis of the healthcare and support needs of Catherine; assessing whether these were fully recognised and understood by professionals, commenting on whether appropriate care, treatment and support services were offered, identifying both areas of good practice and areas for improvement, with particular focus on management of:

a) Type 1 Diabetes

b) Mental Health i.e. dementia, depression, anxiety

c) Capacity and consent - appropriate use of the Mental Capacity Act and Lasting Power of Attorney

2.5 Consider and assess each agency's response to identify and implement any immediate learning following Catherine's death.

2.6 The SAR is asked to additionally consider:

a) Were services co-ordinated?

b) What evidence was there of effective communication and information sharing?

c) The timeliness of interventions for Catherine

d) Risk assessment and risk management.

e) Identification of good practice

[2] https://www.scie.org.uk/safeguarding/adults/introduction/six-principles/

3. Timeline and Methodology

3.1 The review concentrates on the most relevant period, from 18/05/2020 – 09/07/2020. During this two-month time frame, Catherine resided at a residential care home and had two admissions to hospital where ultimately, she sadly died.

3.2 The report is written in line with SAR quality markers[3] and the six principles of adult safeguarding. The methodology included a collaborative approach with stakeholders to agreeing terms of reference with a focus on themes, patterns, and factors together with family discussion. The Independent Reviewer has conducted research by analysing the information provided and by questioning representatives of agencies.

4. Partners involved

The following agencies contributed to the review, through submitting detailed chronologies and written care plans.

Avery Healthcare

York and Scarborough Teaching Hospitals NHS Foundation Trust

Tees Esk and Wear Valleys NHS Foundation Trust

City of York Council Adult Social Care

Primary Care Services

In April 2023, the Independent Reviewer met with Catherine's daughter who was happy to be involved in the SAR process and provided key information about who Catherine was as a person.

5. Pen Portrait

Catherine was born in Oldham, had an older brother and enjoyed a happy childhood. When she left school, she went to commercial college to learn shorthand and typing and worked in various office jobs. In her younger days Catherine was a member of a formation dance team, and they travelled around the country doing displays. Catherine was known to be an independent lady, could be stubborn and knew her own mind. She had married and was widowed and had one daughter. Travel was her passion, she did a world cruise, an African safari and in her life, she had lived in London, York and Spain.

On her return to York Catherine lived in a bungalow close to her daughter's house. Catherine was diagnosed with Type 1 diabetes[4] at the age of thirty and was close to receiving the Alan Nabarro medal[5] which is awarded to people who have lived with

[3] Safeguarding Adults Review Quality Markers - SCIE
[4] https://www.diabetes.org.uk/about-diabetes/type-1-diabetes
[5] https://www.diabetes.org.uk/about-us/about-the-charity/our-areas-of-work/medals.

diabetes for 50 years. Catherine had appointed her daughter as her Lasting Power of Attorney[6] for health and welfare.

6. Overview of key events

Pre-admission period

6.1 Catherine was referred on 02/09/2019 to Improving Access to Psychological Therapies (IAPT) due to symptoms of depression, seeking support and possible medication. Initially she was offered online support, but she struggled with this, and it was agreed that she would wait for 1:1 counselling.

6.2 Catherine was referred to the Mental Health Services for Older People Crisis Team on 29/04/2020 by her General Practitioner (GP) with symptoms of insomnia and suicidal thoughts. Catherine had supportive interventions until 05/05/2020 when discharge back to the care of the GP was agreed.

6.3 On the 18/05/2020 Catherine had a telephone consultation with her respiratory consultant where she commented that her memory had deteriorated. He discussed with her symptoms of chest tightness and the feeling that she was not producing much phlegm. Catherine also described having night panic attacks and a choking feeling. The night symptoms were attributed to Catherine's mental state and cognitive impairment. Some changes were made to medication, but a follow up appointment was not felt to be required.

6.4 A further referral by her GP to the Community Mental Health Team (CMHT) was made on 19/05/2020 when Catherine reported experiencing some memory loss and contact was made with both Catherine and her family. At this point it was advised that all physical investigations be carried out prior to any further mental health involvement.

6.5 Prior to her admission to hospital on 27/05/2020 Catherine had seen her GP due to a deterioration in her general health and memory over a period of approximately 7 weeks. A CT scan of her head was requested.

First admission to York Hospital

6.6 On the 27/05/2020 Catherine was admitted to York Hospital via an attendance at their Emergency Department (ED) with a 2-week history of decreased mobility, increased agitation and confusion and episodes of urine and bowel incontinence. Catherine's daughter accompanied her and said Catherine was unable to manage at home. The ED notes commented that the assessment of Catherine was of increasing confusion, and reduced mobility, which affected her gait. In addition, that she was having difficulty in swallowing plus episodes of incontinence. A CT scan showed no acute pathology, i.e. no recent changes that would account for Catherine's current symptoms.

6.7 Notes suggest that her deterioration was swift, Catherine had been driving the previous week but was now unable to manage medication or walk without shuffling. The records also mention she was experiencing visual hallucinations. Blood tests

[6] https://www.gov.uk/lasting-power-attorney-duties/health-welfare

showed Hyponatremia[7]; and other considered diagnoses were Parkinson's[8]; Lewy Body Dementia [9] and Depression.

6.8 On 28/05/2020 a trusted assessor[10] documented the first stages of discharge planning. The trusted assessor recommended that Catherine would be a good candidate for in-patient rehabilitation.

6.9 Additionally on 28/05/2020 the specialist diabetes team came to the ward to review Catherine. An adjustment to the insulin regime was made and the lunchtime insulin injection was stopped. Notes indicate that twice daily visits for insulin would be required post discharge.

6.10 During her time in York hospital Catherine was considered to have capacity and to be oriented to time and place but was noted to be a little anxious. Catherine completed a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR[11]) on 29/05/2020 with the Medical Consultant with no issues about her capacity to make this decision.

6.11 Additionally on 29/05/2020 nursing notes indicate that Catherine had a Dexcom[12] and that blood glucose levels were stable. Notes reference that the specialist diabetes team need to be informed if transferred as the Dexcom will need changing.

6.12 On 30/05/2020 at 10am Catherine is reviewed on the ward by the diabetes specialist nurse. It is noted that Catherine's Novorapid insulin had been given late that morning and as such she had a postprandial rise in blood glucose, that led to 6 units Novorapid being given. At 12.25pm it is noted that her blood glucose had only reduced to 16.6 mmols on the Dexcom and that Catherine was having a full hot meal and a pudding. Catherine is showing signs of hyperglycaemia i.e. lethargy and thirst. A further 4 units of Novorapid are given. On the same day Catherine consented to physical therapy sessions but subsequently refused to practice the therapy as she felt there was 'no point'.

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[7] Hyponatremia means that the sodium (salt) level in the blood is below normal. Symptoms can include nausea and vomiting, loss of energy and confusion.

[8] Parkinson's https://www.nhs.uk/conditions/parkinsons-disease/

[9] Lewy Body Dementia https://www.nhs.uk/conditions/dementia-with-lewy-bodies/

[10] Trusted assessor schemes are a national initiative designed to reduce delays when people are ready for discharge from hospital. It is based on providers adopting assessments carried out by suitably qualified practitioners working under a formal, written agreement https://www.cqc.org.uk/sites/default/files/20180625_900805_Guidance_on_Trusted_Assessors_agreements_v2.pdf

[11] DNACPR (do not attempt cardiopulmonary resuscitation). This means if a patient's heart or breathing stops the healthcare team will not try to restart it.

[12] Dexcom is a type of continuous glucose monitoring. A sensor attached to the skin sends results to a receiver or mobile phone every few minutes https://www.nhs.uk/conditions/type-1-diabetes/managing-blood-glucose-levels/continuous-glucose-monitoring-cgm-and-flash/ For patients with erratic glucose levels they can be extremely beneficial https://www.diabetes.org.uk/guide-to-diabetes/diabetes-technology/flash-glucose-monitors-and-continuous-glucose-monitors

6.13 On 1/06/2020 the medical notes reference (as on multiple other days) that Catherine was incredibly anxious. Episodes of anxiety are responded to by ward staff providing verbal reassurance to Catherine. Additionally she is often described as being low in mood, for which she is prescribed an anti-depressant.

Rehabilitation Hospital

6.14 On 02/06/2020 it was recorded that Catherine had been awake and anxious all night despite reassurance from the staff. Catherine was transferred to the rehabilitation provision within York Trust services.

6.15 On 03/06/2020 a physiotherapy review meeting documented Catherine's daughter as being anxious about her mother returning home to live with her, as she could not cope with her mother's increased health demands. In the meeting Catherine's daughter also commented that her mum had always stated that she did not want to be put in a 'home'. However, during a physiotherapy session and discussion regarding discharge home, it was recorded that Catherine did discuss preferring 24-hour care and someone to call on for care and company.

6.16 On 05/06/2020 it is recorded that Catherine was experiencing increased anxiety and feeling the need to contact her daughter many times a day for reassurance.

6.17 On 06/06/2020 Catherine is recorded as being anxious about her medication and her blood sugars. At 6am Catherine's blood glucose reading is 18.3 mmols. It is noted that the hospital informed Catherine's daughter of her mother's decision to be discharged to a care home, and it is recorded that Catherine's daughter also felt this was the right decision. However, later on this day the hospital was contacted by the daughter and son in law to state that Catherine had called them saying she wanted to kill herself and stating she had been left to die. At this time Catherine was recorded as being unsettled and wandering about the ward wanting to go home. It was also noted that in the past she had tried to overdose on insulin and was known to the Mental Health Crisis Team.

6.18 On 07/06/2020 Catherine discussed her feelings about the covid lockdown situation stating she felt like an animal. On 08/06/2020 the Wellbeing Co-Ordinator saw Catherine due to her low mood and wanting to go home. Some reassurance was provided, and she is described as being settled back in her room on leaving.

6.19 On 08/06/20 there is noted instruction from the specialist diabetes nurse to ensure that Catherine has her blood glucose and insulin 15-20 minutes pre her meals not post which is currently happening. A further 48 hours of observation is indicated and then feedback to the team for review and consideration of change to the long-acting insulin. It is recorded that this is not currently recommended as Catherine sometimes has a drop in blood glucose at night-time. Later on the same evening Catherine has a hypoglycaemic episode, her blood glucose reading is 3.8 mmols, she eats some supper and it rises to 4.7 mmols. Overnight her readings range between 13 and 19 mmols and at 0650hrs her reading is 16.8mmols.

6.20 On the 09/06/2020 instructions from the medical consultant are to monitor blood glucose levels carefully; to try 'as required' medication to reduce stomach acid; and to start Rivastigmine[13] for now probable diagnosis of Lewy Body Dementia.

6.21 On 10/06/2020 hospital social workers spoke with the ward staff about discharge to a care home. The discharge option was subsequently discussed with Catherine's daughter who was happy with the plans. She reported that her mum was frequently contacting her, advising that she was wanting to harm herself or die, and that she was being left to care for herself. Catherine's daughter reported this was having a negative impact on her own well-being.

6.22 Additionally on the 10/06/2020 the social worker considered the need for an urgent Deprivation of Liberty Safeguard (DoLS) application[14]. The application was not made as it was documented that Catherine had settled and was no longer asking to leave.

Residential Care Home and Primary Care

6.23 The care home is registered with the Care Quality Commission (CQC) to provide *accommodation for persons require nursing or personal care* for up to 80 service users who may be living with dementia, a physical disability or sensory impairment. At the time of Catherine's transfer on 12/06/2020 the care home was rated 'good' in all domains.

6.24 Included in the discharge instructions were that Catherine would require support with her Type 1 diabetes including twice daily administration of insulin and blood glucose monitoring prior to her meals. Catherine was prescribed a once-daily injection of long-acting insulin and twice daily injection of short-acting insulin on a 'sliding scale' i.e. the dose of short acting insulin was dependent on her blood glucose measurement.

6.25 The trusted assessor form did not identify diabetes as being a particular issue, but the discharge letter indicates that Catherine's blood glucose measurements had been erratic throughout her stay in hospital requiring regular reviews from the specialist diabetes team and that ongoing support from the community diabetes team would be needed. The summary advised to maintain the blood glucose range between 6 and 15 mmols and that the Dexcom had not been changed weekly as it should have been, and further advice would be required from the specialist team regarding its use.

6.26 The discharge letter was sent electronically to GP Practice 1, Catherine's GP Practice at her home address. It provided a summary of the hospital care and treatment and informed that Catherine had been discharged to a care home. The information was scanned onto Catherine's health record and misfiled under the date of 25.05.2020.

6.27 On 17.06.2020 Catherine is registered with GP Practice 2 within the catchment area of the care home. As the discharge information is not immediately apparent in

[13] https://bnf.nice.org.uk/drugs/rivastigmine/#indications-and-dose
[14] https://www.gov.uk/guidance/deprivation-of-liberty-orders

the records GP Practice 2 are reliant on the care home to provide the 'new patient' summary and a list of medications.

6.28 During Catherine's stay at the care home it is noted that there were some inconsistencies in the care plans and documentation supporting management of her diabetes. Of note are the following:

- The time of blood glucose measurements and administration of insulin is not always recorded. There are multiple differences in recording between the electronic medication administration record (EMAR) and the hand-written Insulin Administration Record (IAR).
- On 29.06.2020 the long-acting insulin was recorded as having been given at 18 units on the EMAR and 20 units on the IAR. Catherine's blood glucose was recorded as 6.1mmols but with no time recorded to indicate when this was taken. She was given 4 units of short-acting insulin recorded just before 9am which is consistent with a blood glucose reading of between 6 and 10mmols, this was recorded on the EMAR but not on the IAR. There was reference in the daily notes that she had eaten half a jacket potato with beans and half a portion of fruit crumble with custard for lunch. At the evening meal Catherine is derogatory about the food choices she is offered and appeared to refuse all of them and returned to her room. Her blood glucose does not appear to have been recorded and no short-acting insulin was given as she had not eaten.
- On 02.07.2020 only the morning doses are recorded on the IAR, both morning and evening doses are recorded on the EMAR.
- Again on 03.07.2020 the long-acting insulin is recorded as having been given at 18 units on the EMAR and 20 units on the IAR.
- CATHERINE was prescribed Metformin as a long-standing medication to support diabetic control. Her care plan references that Catherine takes Glicazide and lists the side-effects, rather than Metformin.
- At some point the range of acceptable blood glucose readings is changed to being between 6 and 20 mmols. It is unclear when this occurred and why.
- The care plans seen indicate what staff should do in the event of hypoglycaemia (low blood glucose) and hyperglycaemia (high blood glucose). The information relating to hyperglycaemia is unclear – one paragraph stating that symptoms may occur above a reading of 9 mmols and another indicating above a reading of 15 mmols. Both however indicate that the action is to contact the GP.

6.29 On 22.06.2020 following triage by the practice nurse at GP Practice 2 Catherine had a video consult with a GP. She reported feeling chesty and nauseous. It is noted that there is no evidence of a cough or shortness of breath and Catherine is reported as sitting comfortably with no respiratory distress. Catherine informed the GP that the main thing bothering her was nausea and she is given an anti-sickness medication to try. She is told that she may need some further investigations if it does not settle which Catherine agreed to.

6.30 On 25.06.2020 via a phone call a review by the community diabetes specialist nurse is completed. Catherine's recent blood glucose readings have ranged between 18.7 and 22.6 mmol. From the evening of 23.06.2020 to the 26.06.2020 the

maximum dose of short-acting insulin (10 units) had been given twice daily. It was advised that the long-acting insulin is increased by 2 units from 18 units to 20 units daily. This instruction is sent by email to the care home manager to implement.

6.31 On 28.06.2020 a handwritten note is faxed to GP Practice 2 titled 'missing monthly orders'. The note includes missing medications for two residents alongside a list of medications being requested for Catherine. Included in the list is Tresiba 100units/1ml injection (long-acting insulin) and Novorapid Insulin pen 100 units/1ml (short-acting insulin). The fax is followed up with an email the following day, this is sent to the practice email address rather than the prescription request email account which caused some delay in it being responded to.

6.32 On 29.06.2020 a further contact is received from the community diabetes specialist nurse advising that Metformin 500mg twice daily was to be stopped with immediate effect. This decision had been made due to Catherine's age, dementia diagnosis and potential for weight loss, the Consultant Diabetologist agreed that the care home could manage Catherine's diabetes with prescribed insulin, prioritising safety and comfort. Arrangements were made for a telephone call follow up in one week. The instruction was sent by email to the care home reception email account. There is no additional information about what impact this might have on Catherine and what staff should look out for. The end of the email does however say to contact them again if further information is required.

6.33 Following a settled period between 27.06.2020 and 30.06.2020, Catherine's blood glucose increases to 24.2mmols on the evening of the 30.06.2020 and remains at that level on the morning of the 1.07.2020, reducing to 19.7mmol that evening. On the evening of the 2.07.2020 the blood glucose reading is 26.8 mmols and by the 4.07.2020 the meter reads 'HI' indicating a level higher than the meter can show. Catherine is recorded as being unwell. The long-acting insulin is given but the care home had run out of the short-acting insulin, which hadn't arrived with the other medications the day before and so are unable to give this. Despite her blood glucose reading 'HI' Catherine is still told she must try to eat. She reported feeling nauseous but did try to eat some Weetabix and subsequently vomited.

6.34 The care staff contact the pharmacy to request the short-acting insulin but are told that it wasn't on the prescription, therefore it hadn't been supplied. They then contact NHS 111 to request an urgent prescription. As Catherine continues to be unwell the care staff contact NHS 111 again and an ambulance is requested. Initially Catherine says she does not want to go back to hospital; however she is persuaded that she must, and her daughter is in agreement with this decision. Catherine was re-admitted to hospital and diagnosed with diabetic ketoacidosis[15] (DKA).

6.35 When the prescription arrives at the care home later that day it is just a Novorapid pen without insulin that has been dispensed as that is what had been

[15] Diabetic Ketoacidosis (DKA) is where a lack of insulin causes harmful substances called ketones to build up in the blood. It can be life threatening and needs urgent treatment in hospital https://www.nhs.uk/conditions/diabetic-ketoacidosis/

prescribed by the out of hours GP. It is the Novorapid Flexpen pre-filled with insulin that is on the discharge information from the hospital.

Second Admission to York Hospital

6.36 Catherine is admitted to the Intensive Care Unit (ICU) and is treated on the DKA pathway. It is recorded by multiple staff that Catherine stated that she wanted to die and did not want to be treated. DNACPR is recorded as being in place as is Catherine's daughter having Lasting Power of Attorney for Health and Welfare[16]. Blood glucose is recorded as being above 30 mmols and ketones are greater than 6 mmols. A safeguarding concern is raised regarding the care home running out of insulin. It is recorded that there are no other clear causes for DKA found.

6.37 Treatment for DKA is documented as being problematic due to difficulties obtaining intravenous (IV) access and multiple attempts are made to re-insert a cannula and maintain viable IV access. Following initial treatment, notes record that although blood glucose levels remain greater than 30 mmols the acidosis has resolved.

6.38 On 7.07.2020 between 11pm and midnight Catherine is moved from ICU to a general medical ward. Both Catherine and her daughter are upset by the move so late at night. Additionally, there is an incident of a staff member recorded as not attending to Catherine due to her rudeness to staff. By now Catherine is refusing any observations being recorded and refusing insulin treatment. She is recorded on the previous day as having capacity to make the decision to refuse. She states that she wants to be kept comfortable and wants to die. She accepts drinks, ice-cream, and Paracetamol but refuses all other medication. Catherine is referred for a palliative care review and to the Mental Health Liaison Psychiatrist for assessment.

6.39 An initial review takes place by telephone call between Catherine and the Consultant Psychiatrist; Catherine expresses quite clearly her reasons for refusing treatment knowing it will result in her death.

6.40 On 8.07.2020 Catherine is reviewed by the Palliative Care team and the Consultant Psychiatrist. There are comprehensive notes written by the Psychiatrist following discussion with Catherine and her daughter. It is recorded that Catherine's mother died of dementia and that she did not want the same for herself. She had expressed a wish to die before her diagnosis of dementia; she missed her husband and had enjoyed her life with him but had much less enjoyment since his death. Catherine's is aware of her frailties and what the future holds for her. It is recorded that Catherine's daughter is supportive of her mother's wish to die.

6.41 The Palliative Care team, on their review, note concern regarding the ongoing appropriate management of Catherine's wishes in view of legal and ethical considerations. The case is discussed with the hospital safeguarding team. It is agreed that the case should be raised with the hospital ethics committee as a matter of urgency.

[16] https://www.gov.uk/lasting-power-attorney-duties/health-welfare

6.42 It is agreed between the medical staff that Catherine's mental health is having an impact on her decision-making. As Catherine had her last insulin on 6.07.2020 she is now recorded as confused and appearing delirious likely due to further DKA. The medical teams (with additional advice from the hospital legal team) agree that they will recommence treatment for DKA in Catherine's best interests. It is recorded that this is carried out under the Mental Capacity Act not the Mental Health Act and that treatment will enable further capacity assessment to be carried out. Catherine's daughter is recorded as understanding that the medical staff have a duty of care towards her mother whilst aligning with Catherine's wish to die.

6.43 Just after 4pm on 8.07.2020 as the DKA treatment is started Catherine sadly takes her last breath and dies with her daughter sitting beside her holding her hand.

7. Findings & recommendations

a) Type I Diabetes

Finding One:

Diabetes management was not given the level of priority needed for safe care once Catherine became unable to manage it herself.

After almost fifty years of living with and managing her Type 1 Diabetes, it sadly ultimately was the cause of Catherine's death. Catherine presented with complex symptoms of confusion, reduced mobility, deranged bloods, and episodes of incontinence, that had developed over a few short weeks and meant that she was unable to self-care at home and unable to manage her diabetes independently. Her journey through hospital wards and discharge to the care home added a level of complexity to her diabetes care which made it more of a challenge to manage. Changes in environment; diet and fluid intake; poor physical and mental health would all have an impact on blood glucose levels.

Catherine should have been able to rely on the health and care system to provide the care that she was not able to do for herself, however there were lapses and inconsistencies in care delivery which culminated in the development of ketoacidosis requiring urgent hospital (re)admission.

In summary:

- There was inconsistency of staff following the prescribed care plan of recording blood glucose pre-meal and administering short-acting insulin before breakfast and evening meal. In the hospital it is recorded to be of concern by senior clinicians reviewing diabetes care on more than one occasion that staff are not following the care plan as requested and need to do so, in order that prescribed treatment is administered based on accurate recording. Similarly in the care home there were several times that recordings were not completed as they should have been.
- Treatment changes were made that would potentially have a significant impact and potentially warranted Catherine's blood glucose being more closely monitored but that did not appear to either be requested or take place, i.e. lunchtime insulin stopped; Metformin stopped; long-acting insulin dose increased

by 2 units. When blood glucose levels were outside of the acceptable range and insulin was given, there was a lack of subsequent recording to ascertain that treatment had been effective.

- The use of the Dexcom which Catherine had relied upon to let her know when her blood glucose levels were a concern appeared to have been discontinued. There is reference to it requiring changing but no evidence in the records seen that it was changed and was being used.
- There appeared to be a greater emphasis on the avoidance of hypoglycaemia and therefore less consideration of the potential for hyperglycemia. The signs and symptoms of both were evident during Catherine's first hospital stay. This information did not appear to follow Catherine to the care home. The monitoring of ketones does not appear to have been a consideration but may well have helped in recognising a developing ketoacidosis.
- Catherine often complained of feeling sick and regularly required anti-sickness medication to manage this. Sick day rules[17] do not appear to have been part of the information available.
- Information provided on the care plan in the care home regarding hyperglycemia was contradictory and lacked any mention of ketoacidosis. At some point the range of acceptable levels changed from between 6 and 15 mmols to a higher level of between 6 and 20 mmols, it is not clear why or when this occurred. In the days before the second admission the recorded levels of just over and under 20 mmols were likely tolerated as being just outside of acceptable. No contact appears to have been made to either a GP or the diabetes specialist team to advise them that this could be a concern as per care plan instructions.
- There were multiple incidences where the flow of information did not go as intended. The discharge letter had gone to GP1 but had been misfiled in Catherine's records. Catherine did not trigger immediately as a new patient when she was registered with GP2. The GP review on the 22.06.2020 was a missed opportunity to go through all Catherine's medications and put them on the appropriate ordering regime. When the care home staff ordered the medication, it was done as a missed order rather than a new prescription with the result that the short-acting insulin was not supplied.
- When the short-acting insulin supply ran out efforts made to obtain a prescription from the Out of Hours GP led to misinformation about the correct insulin required with the result that just a pen without any insulin was supplied, albeit that Catherine had been transferred to hospital by the time it arrived.
- The request for medication was initially faxed to the GP surgery and then resent to a general email account rather than the dedicated prescription account which added a further delay to the response time.
- Information from the diabetes specialist nurses regarding changes to treatment was emailed to different accounts at the care home, one to the reception email account and another to the manager's email. Whilst both were responded to appropriately a standard operating process for information would be more advisable as best practice.
- The innovation by the care home of managing diabetes care in a residential setting, undertaking tasks which would usually be done by the District Nursing Team to relieve some of the pressure from them and also reduce footfall into the home during the period of the Covid-19 pandemic is seen as good practice. The

[17] https://www.diabetes.org.uk/living-with-diabetes/life-with-diabetes/illness

home had a policy and procedure in place and relevant staff received training to support their knowledge and understanding of diabetes and also to administer insulin injections from a pre-filled pen. However, Catherine was one of the first, if not the first, resident to be admitted requiring that care and the level of complexity was likely not fully appreciated by those undertaking her care.

Recommendation 1

City of York Safeguarding Adults Board to request that relevant partners complete a review of the current pathway for diabetes care from hospital to home to consider the lapses identified in care, provide assurance against changes already made and instigate any necessary improvements to include relevant policy and procedures; information for professionals and for carers; staff training; care delivery; and ordering and supply of insulin. The timeline for the review to be set by partners.

b) Mental Health i.e. dementia, depression, anxiety

Finding two

Mental Health Specialist Services appeared to have a positive impact on Catherine when they were involved in her care. A timelier involvement of specialist psychological services following the diagnosis of Lewy Body Dementia may likely have had a positive influence on Catherine's care and enabled her to feel supported and better understood by those caring for her, although it may not have changed the outcome for her.

It is documented throughout Catherine's records that she experienced poor mental health with symptoms of anxiety, depression and unhappiness at her circumstances. These symptoms were consistent with the subsequent diagnosis of Lewy Body Dementia. An earlier referral for specialist psychological services following diagnosis could have been considered, particularly as she was known to them pre-diagnosis.

Catherine's loss of independence and subsequent diagnosis occurred rapidly over a few short weeks. Although she is reported as being in favour of a move to a care home this also represented a major life change. The short period of three weeks that Catherine spent in the care home did not really allow time for staff to get to know her fully and for her to get to know the staff and other residents. She is reported as being unsettled and of not eating well. The move to the care home also meant a change of GP to a new practice where equally staff would not know her or readily be aware of her history.

It is acknowledged that Catherine's symptoms may not have appeared to reach a threshold for requirement of specialist intervention until the second admission, by which time sadly the opportunity for any meaningful intervention was gone.

In summary:

- During 2019 Catherine asked for help with her mental health and was appropriately referred to community mental health services by GP1. Although Catherine struggled with the offer of online support, she was subsequently added to the waiting list for 1:1 counselling.

- In the month before her first admission to hospital Catherine was referred to the Older People's Crisis Team by GP1 with symptoms of insomnia and suicidal thoughts. She had supportive interventions which appeared to have a measure of success, and she was discharged back to the care of GP1.
- When Catherine's mental health symptoms worsened and associated physical symptoms developed, the advice from the mental health team was to rule out any physical causes for the deterioration in her mental health before any further psychological interventions would be considered. Catherine was admitted to hospital soon after for investigations.
- Alongside other co-morbidities Catherine was subsequently diagnosed with Lewy Body Dementia, and she was commenced on medication to help management of this. Depression and anxiety are known to be typical symptoms associated with Lewy Body Dementia. There are frequent references to Catherine being anxious.
- Initially whilst undergoing investigations in hospital Catherine's anti-depressant medication was stopped, however it was recommenced when symptoms of depression became apparent.
- Whilst in hospital Catherine expressed unhappiness about lockdown and 'feeling like an animal' and that she wanted to go home. Catherine told her daughter that she wanted to die, and it was shared that she had previously tried to end her own life by overdosing on insulin. It is not evident from records that the mental health team had ongoing input during Catherine's first hospital admission or during the three weeks in the care home.
- DNACPR is signed by Catherine following a conversation with her Hospital Consultant. The conversation offered an opportunity to discuss and document Catherine's personal views and wishes for care and treatment at the end of her life, but it is not obvious in records that this took place.
- Catherine's anxiety and depression did not give staff sufficient cause for concern that referral to specialist psychological services was considered. It is perhaps that Catherine is given reassurance by staff in hospital and in the care home and this appears to have the effect of settling or distracting her for periods of time, that a referral is not made.
- Catherine also seeks reassurance from her daughter, often making calls to her several times per day. Her daughter reports that the volume and content of calls from Catherine started to have a detrimental impact on her own well-being.
- An urgent referral to mental health services is made during the second admission when Catherine refuses treatment for ketoacidosis despite initially being receptive to it and it is considered that an underlying depression may be impacting her capacity to refuse treatment.
- Extensive notes are written by the Consultant Psychiatrist which provide a more comprehensive picture of Catherine's life and a clearer picture that her wish to die had been one stated for several weeks and was not wholly a response to her current and immediate situation.
- An agreed best interests decision to recommence treatment is made too late to prevent her death.

Recommendation 2

City of York Safeguarding Adults Board should share the learning from the review to remind practitioners to maintain a low threshold for referral to Mental Health Psychological / Specialist Older People's Services where an individual with existing symptoms of depression and anxiety has a new diagnosis of

dementia associated with a loss of independence and a change of accommodation.

Recommendation 3

City of York Safeguarding Adults Board should seek an update for assurance purposes on the implementation across the health care system of the ReSPECT tool which enables and documents a meaningful conversation that goes beyond DNACPR and considers a person's views and wishes of care and treatment towards the end of their life
https://www.resus.org.uk/respect/respect-healthcare-professionals

c) Capacity and consent - appropriate use of the Mental Capacity Act and Lasting Power of Attorney

Finding 3

For much of the period of care and treatment covered by the review Catherine is presumed to have capacity, and this is not questioned. She is provided with information, is involved in decision-making about her future care and treatment, and her choices and wishes are respected. This is in line with the Mental Capacity Act and is seen as good practice.

There are times when Catherine is anxious or has periods of confusion that her capacity could be argued as fluctuating, but these are of short duration and again it is viewed that the practice followed is in line with the Mental Capacity Act.

Closer scrutiny is applied to Catherine's capacity when a second admission to hospital is advised. She is persuaded to change her first 'unwise decision' that she does not want to go back to hospital and consents to be transported in the ambulance. Her subsequent decision to refuse treatment is a challenging one for clinical staff and this ultimately resulted in her death.

In summary:

- During her first admission Catherine signs a DNACPR form with the Consultant with no issue about her capacity to make the decision. She accepts care and treatment and for the most part settles with reassurance from staff when she is anxious.
- A few days before discharge to the care home Catherine expresses a wish to leave the hospital and an urgent DoLS application is considered by the social worker. It is documented that the application is not made because Catherine is settled and is no longer asking to leave. This illustrated a time when capacity could be described as fluctuating. Although perhaps clumsily written (i.e. just because someone is not asking to leave does not mean that they are not deprived of their liberty[18]) it is considered to be a proportionate response that an

[18] https://mca-adults.trixonline.co.uk/chapter/identifying-a-deprivation-of-liberty

urgent application is not required. Catherine is involved with her discharge planning and following a conversation with the well-being co-ordinator returns to her room. There is no mention that her return is under duress or that once she receives reassurance, she lacks capacity to make the decision to remain on the ward.

- Catherine is involved in discharge planning and makes the choice herself to be discharged to a care home. She recognises that she needs help to manage her insulin and other medications and voices that she wants to go to a care home so that she has people on hand when she needs them.
- When Catherine becomes unwell in the care home with symptoms of hyperglycaemia it is advised that she needs hospital admission. Initially she indicates that she does not want to go back to hospital, it is documented however that she does eventually agree and consents to being transported by ambulance.
- After initially consenting to treatment for ketoacidosis Catherine then refuses for this to continue. She declines any monitoring or observations and is considered to have capacity to refuse treatment. It is documented that she understands what will happen without treatment i.e. that she will die.
- Appropriate referrals are made to both the palliative care team and to the mental health team. Valid discussions are held with the hospital safeguarding and legal team.
- It is recorded that Catherine's daughter had a relevant Lasting Power of Attorney (LPA), as such she is part of the discussions about Catherine's healthcare and is kept informed of decisions made by the clinical team. She is appropriately not asked to make the decision about life-saving treatment in Catherine's best interests as this is not an applicable decision under LPA unless Catherine had made an advanced decision, which she had not (see appendix 1).
- Ultimately treatment is restarted beyond a point where it will change Catherine's wish and she passes away peacefully.

Good practice is demonstrated by practitioners in what are difficult and challenging circumstances and relevant referrals are made. Consideration has been given as to whether if the decision to treat had been made earlier and had been effective that this would have made a difference to Catherine. The conclusion drawn from reviewing the records available is that it would only have prolonged Catherine's distress and wouldn't necessarily have changed her mind.

Recommendation 3 is relevant as it would have provided an opportunity for Catherine to express and record her views and wishes at a 'less acute' time and may have helped clinicians with their decision-making in the final acute situation. No additional recommendation is considered necessary, other than practitioners may want to reflect on the case and use as an example in MCA training.

Covid-19

It is important to note that the key events of this review occurred at the start of the Covid Pandemic and during the first official lockdown of the country. The pandemic presented significant challenges to adult safeguarding law and practice, local authorities were underprepared and struggled to undertake key functions as did all

partners and agencies. It is noted that the Coronavirus Act 2020 included scope of widespread suspension of key duties under adult social care legislation, which resulted in concerns that adults who required care and support were not having their needs met. It is noted that significant change occurred in the delivery of services during this period including the increase of remote working and remote assessments and care planning, those classed as vulnerable shielding, including the health and social care workforce.

It is recorded that Catherine is affected by the restrictions put on her by lockdown and it is acknowledged how difficult and distressing it must have been for her being cared for in different settings by (the majority of) staff wearing masks and necessary personal protective equipment (PPE). As far as is known Catherine was effectively shielded against the virus although undoubtedly, she suffered, as did many, from increased anxiety around it.

Equality Act 2010

The Equality Act provides protection from discrimination based on a range of protected characteristics. Disability is one of the specified protected characteristics and Catherine's symptoms and subsequent diagnosis of dementia would meet the definition to be identified as such and therefore be protected by the Act. Following the scrutiny of available information the review does not consider that Catherine suffered any lasting discrimination based on her disability. During the second admission there is reference in records that Catherine informed her daughter that ward staff told her they would not attend due to her rudeness towards them. This incident was raised as a complaint by Catherine's daughter, and a promise of investigation is given by the ward manager. The incident is considered to be an isolated episode of poor practice by the staff and not evidence of discriminatory abuse.

8 Conclusion

Catherine had lived with diabetes for much of her life. This review notes with sadness that it became the cause of her death. Cumulative factors of lapses in best practice managing her diabetes and her deteriorating physical and mental health resulted in her readmission to hospital where ultimately, she took the decision to refuse any further care.

Learning is identified mainly in the delivery of diabetes care and also in the importance of mental well-being and planning and documenting choices and wishes for end of life care. There is good practice noted in the application of the Mental Capacity Act and that Catherine for the most part was involved in decision-making about her care and her choices were respected.

9. Acknowledgements

The City of York Safeguarding Adults Board wishes to extend sincere condolences to Catherine's family on her untimely death and thanks them for their contributions to the review. The City of York Safeguarding Adults Board would also like to thank the

partners and agencies who were part of the review for their openness and contributions to the review.

10. Summary of recommendations

Recommendation 1

City of York Safeguarding Adults Board to request that relevant partners complete a review of the current pathway for diabetes care from hospital to home to consider the lapses identified in care, provide assurance against changes already made and instigate any necessary improvements to include relevant policy and procedures; information for professionals and for carers; staff training; care delivery; and ordering and supply of insulin. The timeline for the review to be set by partners.

Recommendation 2

Practitioners should maintain a low threshold for referral to Mental Health Psychological / Specialist Older People's Services where a diagnosis of dementia is associated with a loss of independence and a change of accommodation.

Recommendation 3

Use of the ReSPECT tool should be promoted across the health care system (where a life-limiting condition is diagnosed) to facilitate and document a meaningful conversation that goes beyond DNACPR and considers a person's views and wishes of care and treatment towards the end of their life
https://www.resus.org.uk/respect/respect-healthcare-professionals

Appendix 1

Excerpt below taken from Mental Capacity Act 2005 Code of Practice
https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice
(Chapter 7)

Personal welfare LPAs that authorise an attorney to make healthcare decisions

7.26 A personal welfare LPA allows attorneys to make decisions to accept or refuse healthcare or treatment unless the donor has stated clearly in the LPA that they do not want the attorney to make these decisions.

7.27 Even where the LPA includes healthcare decisions, attorneys do not have the right to consent to or refuse treatment in situations where:

• ***the donor has capacity to make the particular healthcare decision (section 11(7)(a))***

An attorney has no decision-making power if the donor can make their own treatment decisions.

• ***the donor has made an advance decision to refuse the proposed treatment (section 11(7)(b))***

An attorney cannot consent to treatment if the donor has made a valid and applicable advance decision to refuse a specific treatment (see chapter 9). But if the donor made an LPA after the advance decision and gave the attorney the right to consent to or refuse the treatment, the attorney can choose not to follow the advance decision.

• ***a decision relates to life-sustaining treatment (section 11(7)(c))***

An attorney has no power to consent to or refuse life-sustaining treatment, unless the LPA document expressly authorises this (See paragraphs 7.30–7.31.)

• ***the donor is detained under the Mental Health Act (section 28)***

An attorney cannot consent to or refuse treatment for a mental disorder for a patient detained under the Mental Health Act 1983 (see also chapter 13).