Leicester Safeguarding Adults Board

WORKING IN PARTNERSHIP
TO KEEP ADULTS SAFE

SAFEGUARDING ADULTS REVIEW
Rosey

2022

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SAFEGUARDING ADULTS REVIEW – Rosey

Leicester Safeguarding Adults Board

1. INTRODUCTION.

1.1 Rosey had a diagnosis of schizophrenia. In the months preceding Rosey's death, a Community Psychiatric Nurse (CPN) visited her home every three weeks to administer medication.

1.2 On 20/10/20 Rosey's CPN contacted Leicestershire Police as Rosey had not been answering the door. They attended and on entry they had concerns about the state of Rosey's home and her self-neglect. The police submitted a Public Protection Notice.

1.3 Subsequently Adult Social Care (ASC) and Rosey's CPN attempted to visit Rosey, but as there was no response on 11/11/20 a mental health assessment was requested.

1.4 Due to the lack of response to visitors, a warrant was obtained to enter Rosey's property. On the evening of 11/11/20 the Approved Mental Health Professional (AMHP), doctors, police and Rosey's family met at Rosey's property. Rosey was found collapsed, an ambulance was called, and Rosey was admitted to hospital. On admission, Rosey was found to have late-stage breast cancer and was referred to palliative care. Rosemary subsequently died on 24/11/20. Her death certificate lists the causes of death as being pneumonia and breast cancer.

2. SAFEGUARDING ADULTS REVIEWS

2.1 Section 44 of the Care Act 2014 places a statutory requirement on the Leicester Safeguarding Adults Board (LSAB) to commission and learn from SARs (Safeguarding Adults Reviews) in specific circumstances, as laid out below, and confers on Leicester Safeguarding Adults Board the power to commission a SAR into any other case:

'A review of a case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs) if –

a) *there is reasonable cause for concern about how the Safeguarding Adults Board (SAB), members of it or other persons with relevant functions worked together to safeguard the adult, and*

b) *the adult had died, and the SAB knows or suspects that the death resulted from abuse or neglect…, or*

c) *the adult is still alive, and the SAB knows or suspects that the adult has experienced serious abuse or neglect.*

The SAB may also –

Arrange for there to be a review of any other case involving an adult in its area with needs for care and support (whether or not the local authority has been meeting any of those needs).

…Each member of the SAB must co-operate in and contribute to the carrying out of a review under this section with a view to –
a) identifying the lessons to be learnt from the adult's case, and
b) applying those lessons to future cases.

2.2 Board members must co-operate in and contribute to the review with a view to identifying the lessons to be learnt and applying those lessons to the future (s44(5), Care Act 2014).

2.3 The purpose and underpinning principles of this SAR are set out in LSAB document: Safeguarding Adults Review Policy https://www.leicester.gov.uk/media/185725/lsab-sar-policy-2018.pdf

2.4 All LSAB members and organisations involved in this SAR, and all SAR panel members, agreed to work to these aims and underpinning principles. The SAR is about identifying lessons to be learned across the partnership and not about establishing blame or culpability. In doing so, the SAR will take a broad approach to identifying causation and will reflect the current realities of practice ("tell it like it is").

2.5 This case was referred to the LSAB on 15/01/21 for their consideration of a Safeguarding Adults Review.

2.6 The SAR Subgroup determined that the criteria for a SAR had been met.

2.7 The Safeguarding Adults Review was led by Patrick Hopkinson who is an Independent Consultant in Adult Safeguarding and who had no previous involvement with this case and no connection with the agencies that worked with Rosey.

3 BRIEF SUMMARY OF CHRONLOGY AND CONCERNS

3.1 Rosey was born in 1964. She was described by her siblings as fun loving and well liked. Rosey was an avid Leicester City Football Club supporter and held a season ticket. Rosey liked music, parties and fancy dress and she was skilled at arts and crafts, including painting and sewing. Rosey entertained her nephews and nieces and would make things for them. Rosey worked for a hosiery manufacturer and managed accounts with retailers. Rosey organised social events for her work colleagues including days out and annual dinners. Rosey was, however, made redundant in 2001.

3.2 Rosey had a happy childhood and enjoyed school. Rosey had six brothers and sisters. Her mother brought all seven siblings up largely on her own as Rosey's mother and father divorced when she was 10 years old. Rosey's siblings described their mother as "the world" to all of them, but it "really hit Rosey" when their mother died in 2000. Rosey had described her mother as her "soul mate".

3.3 Rosey held a Leicester City Council (LCC) housing tenancy from August 2002 and prior to this, she had lived with one of her sisters. It appears that Rosey then lived alone until the time of her death.

3.4 Rosey had four episodes of care from Leicestershire Partnership NHS Trust (LPT) commencing in 2001.

3.5 On 18/5/01 Rosey attended an outpatients mental health appointment. At this appointment Rosey's family reported that she "had not grieved properly" following the death of her mother. Rosey had been prescribed anti-depressants by her GP, but she did not take them.

3.6 Rosey had four hospital admissions under the Mental Health Act 1983 in 2001, 2008 and 2010. During these episodes Rosey showed symptoms of psychosis, such as delusional beliefs and hallucinations (known as "positive" symptoms). From 2012, Rosey received treatment from LPT's Community Mental Health Team. At the time of her death, Rosey was receiving treatment from the City Central Community Mental Health Team's Community Psychiatric Nurse (non-medical prescriber) via three weekly visits and an annual review from a Consultant Psychiatrist.

3.7 Rosey was prescribed anti-psychotic medication (Flupentixol) and in 2016, following sporadic compliance with this, Rosey's CPN began to administer Rosey's depot injection at home. The CPN was accompanied by a GP on the second visit for this, who gave Rosey a physical examination. This revealed no cause for concern, but when asked to attend hospital for a chest x-ray, Rosey refused stating that "if I have cancer, I don't want to know about it".

3.8 In June 2016 Rosey's mental state was described as poor and she was self-isolating and withdrawn. Rosey appeared unkempt and asked, "what is the point in life?", but denied being suicidal. Whilst Rosey did not display positive symptoms of psychosis such as delusional beliefs or hallucinations, there was evidence of negative symptoms such as lack of motivation culminating in poor self-care, disengagement from her family and clinical staff, and lack of

engagement in social activity. As a result of Rosey's decline in her mental state and decreased motivation to get dressed, open the curtains or grocery shop, the CPN, a non-medical prescriber, increased Rosey's anti-psychotic medication in liaison with a psychiatrist.

3.9 In July 2016 a social care assessment was carried out jointly by ASC and Rosey's CPN. During the assessment Rosey disclosed that she had not washed her hair for four months, nor had she done any washing and she had no clean clothes and bed sheets.

3.10 It was noted in the assessment that Rosey had a persistent cough, but she declined any further investigations by her GP or referral for an X-ray. Rosey said that she was fearful of hospitals, and that she did not want to know what the outcome of any tests might be. Rosey spoke for the second time about her belief that she had cancer. The CPN contacted the GP surgery for blood screening because of this and Rosey's refusal to have a chest x-ray.

3.11 The assessment concluded that Rosey did not have care and support needs because she was independent with all aspects of daily living. However, Rosey was referred to an independent living service (which is now no longer in existence), to support her with social isolation

3.12 In January 2017 Rosey was allocated a new CPN.

3.13 In 2018 Rosey's home was noted to be unkempt and cluttered with many packages including microwave meals and empty drinks bottles and in January 2019 the light bulbs in Rosey's flat were not working and her bath was described as full of bags.

3.14 In 2018 Rosey missed her annual appointment with her psychiatrist and rebooked it for 2019.

3.15 In February 2019 Rosey reported that after missing her antipsychotic depot she had begun to feel suicidal. However, Rosey had no suicide plan or intent. Rosey's CPN increased the dose of antipsychotic medication and decreased its frequency (to three-weekly), to reduce the need for Rosey to collect it. This led to a reduced number of visits to Rosey's home, from 26 to 17 a year.

3.16 In March 2019 Rosey's CPN reported of Rosey's clothes being soaked in urine.

3.17 According to LPT, on several occasions Rosey's CPN offered to refer her for another care and support needs assessment, but Rosey refused this. The CPN openly discussed self-neglect with Rosey, but this seemed to prompt Rosey to disengage with the CPN, for example by not allowing the CPN into her home.

3.18 Throughout 2019 Rosey's self-neglect increased and her clothes were described as wet with urine.

3.19 In June 2019 Rosey would not allow her CPN access to her home and the CPN raised her increasing concerns at the Community Mental Health Teams' multi-disciplinary team meeting.

3.20 On 20/12/19 Rosey told her CPN that she had high levels of anxiety.

3.21 In 2020 with the onset of the Covid-19 pandemic the CPN system changed and CPNs were rostered to visit clients on a Depot Nurse Rota. As a result, Rosey was visited by other CPNs not just her allocated CPN.

3.22 During 2020 Rosey sometimes complained of feeling nauseous and her self-neglect became worse. Different CPNs regularly reported body odour, rotting rubbish, unsanitary conditions, flies, coins all over the floor, "tens" of empty bottles and Rosey being clothed in dirty pyjamas. Despite this, between July and September 2020 some improvement in the state of Rosey's home was noted.

3.23 On 5/10/20 one of the CPNs told Rosey that if there were any continued significant concerns about managing her environment and self-care then the CPN would need to liaise with the Council. Rosey seemed quite anxious about the prospect of the Council getting involved.

3.24 On 8th, 9th, 12th and 20th October 2020, Rosey did not answer visits from the depot rota CPN.

3.25 On 20/10/20 the Police attended Rosey's flat. Rosey answered the door. Police Officers described the flat as in very poor condition with plaster hanging from the walls. The main living room was littered with empty milkshake and cola bottles and the bathroom had no functioning shower head. The bath was reported as being full of toilet roll cartons and other rubbish. The kitchen sink was full of mouldy water and the fridge was not working.

3.26 Police Officers submitted a public protection notice (PPN) to their Adult Safeguarding Hub although Rosey did not want any additional support. The Adult Safeguarding Hub shared the content of the PPN with Rosey's GP and ASC and suggested that Rosey would benefit from more frequent carer contact or a social worker.

3.27 On 21/10/20 a CPN visited Rosey, unaware of the PPN.

3.28 On the 26 and 27/10/20, ASC contacted Rosey's regular CPN. A social worker spoke to the CPN about self-neglect and how it may be treated as a safeguarding concern, or the Vulnerable Adults Risk Management (VARM) guidance, which could be used. The social worker advised the CPN to refer Rosey directly to the Adult Mental Health (AMH) Central Social Work team, as is the usual pathway for professional-to-professional AMH referrals. The social worker also transferred Rosey's case to AMH, to ensure it was brought to their attention.

3.29 On 30/10/20 ASC tried to visit Rosey. It was found later that they had visited the wrong address. This appears to have been a human error.

3.30 On 10/11/20 the CPN and a Social worker attended Rosey's home but could not get a response.

3.31 On 11/11/20 the CPN and social worker visited separately. The CPN visited first. On no response, they requested an assessment under the Mental Health Act. In the meantime, the social worker visited but also received no response. Following the CPN's request, an Approved Mental Health Professional (AMHP) called the Police requesting assistance to execute a Section 135 (1) Warrant.

3.32 Later on 11/11/20 the AMHP and the police attended Rosey's home. Again, there was no response but given the escalating concerns for Rosey's welfare, the Police decided that forced entry was necessary under Section 17 Police and Criminal Evidence Act 1984 (PACE policing power to enter and search any premises to, amongst other purposes save life and limb).

3.33 Rosey was found on the kitchen floor, conscious and breathing but disorientated, cold and with slurred speech. There was mottling to her stomach and ulceration to her left breast. Rosey's family were contacted and attended. An ambulance was called and in the early hours of 12/11/20, Rosey was admitted to the Leicester Royal Infirmary.

3.34 On admission Rosey was diagnosed with late-stage breast cancer. It was thought that the cancer had spread to her lungs and possibly liver and palliative care was provided.

3.35 On 24/11/20 Rosey died in hospital aged 57 years old. Her death certificate recorded the cause of death as pneumonia and breast cancer.

3.36 The circumstances leading to Rosey's death were subsequently deemed by ASC to have met the threshold for a s42 adult safeguarding enquiry and on 21/12/20, a month after Rosey's death, a safeguarding enquiry began.

4 THE EVIDENCE BASE FOR THE REVIEW

4.1 Michael Preston-Shoot (2019) argues that, "*Drawing on existing evidence about effective practice would mean that reviewers are not starting out with a blank canvas. What is proposed here is that SARs begin explicitly with the available evidence-base, using it as a lens with which to scrutinise case chronology and explore through panel meetings, interviews and learning events with practitioners and managers what facilitates good practice and what presents barriers to effective practice"*

4.2 The advantage of this approach is that, *"The emphasis then is less on description and more on immediate reflection and systemic analysis of facilitators and barriers, across nationally determined policy, legal and*

financial systems as well as local arrangements and staff values, knowledge and skills" (Preston-Shoot, 2019).

4.3 Consequently, a study was made of both the research evidence and practice evidence that provides insight and guidance when working with someone in Rosey's situation: self-neglecting and with whom services found it difficult to engage.

4.4 **Evidence from research**

4.5 Self-neglect is one of the ten categories of abuse and neglect specified in the adult safeguarding sections of the Care Act statutory guidance. It is clear from the information provided by agencies for this SAR that certainly in the last four years of her life, Rosey was self-neglecting, and possibly well before that time.

4.6 Self-neglect can be defined as, "*the inability (intentional or non-intentional) to maintain a socially and culturally accepted standard of self-care with the potential for serious consequences to the health and well-being of the self-neglecter and perhaps even to their community*" (Gibbons et al, 2006, p.16).

4.7 Suzy Braye, Michael Preston-Shoot and David Orr have undertaken extensive research into, and provided guidance on, working with people who self-neglect and this was available from December 2018 onwards. It was available therefore during the last twenty-three months of Rosey's life and it is appropriate to use this guidance as a framework within which to understand practice with Rosey and to support practitioners facing similar situations of self-neglect in the future. For the purposes of this SAR, it is sufficient to focus only on a summary of this guidance.

4.8 Practice with people who self-neglect is more effective where practitioners:

a) Seek to understand the meaning and significance of the self-neglect, taking account of the individual's life experience

b) Work patiently at the pace of the individual, but know when to make the most of moments of motivation to secure changes

c) Keep constantly in view the question of the individual's mental capacity to make self-care decisions

d) Communicate about risks and options with honesty and openness, particularly where coercive action is a possibility

e) Ensure that options for intervention are rooted in a sound understanding of legal powers and duties

f) Think flexibly about how family members and community resources can contribute to interventions, building on relationships and networks

g) Work proactively to engage and co-ordinate agencies with specialist expertise to contribute towards shared goals

In order to do this, the following approaches should be used:

a) History taking. Explore and ask questions about how and when self-neglect started.

b) Be proactive and identify and address repeated patterns of behaviour

c) Try different approaches, use advocates and concerned others, raise concerns, discuss risks, maintain contact, avoid case closure

d) Ongoing assessment review of mental capacity

4.9 On a more strategic level the policy, procedural and organisational environments that foster this way of working are likely to have the following characteristics:

a) Agencies share definitions and understandings of self-neglect

b) Interagency coordination and shared risk-management is facilitated by clear referral routes, communication and decision-making systems

c) Longer-term supportive, relationship-based involvement is accepted as a pattern of work

d) Training and supervision challenge and support practitioners to engage with the ethical challenges, legal options, skills and emotions involved in self-neglect practice

4.10 The extent to which these approaches were applied to Rosey, and the environment to support them existed, provide a useful analytical framework for this SAR.

4.11 **Self-neglect, mental capacity and freedom of choice**

4.12 Safeguarding Adults Reviews (amongst others: Andrew, Staffordshire and Stoke, 2022; Harold, Brent 2022; Adults B and C, South Tyneside; Mr I, West Berkshire and W, Isle of Wight) have increasingly focused on the challenges of balancing freedom of choice and self-determination with the legal duties (for example under the Human Rights Act 1998 - see Appendix 1 - and the Care Act 2014) and the public expectations and moral imperatives of public services.

4.13 These are further complicated by confusion in the application of the Mental Capacity Act and its statutory guidance (see for example, the post-legislative scrutiny report of the House of Lords Select Committee on the Mental Capacity Act 2005 published in 2014). The Mental Capacity Act applies a set

of principles when considering questions of whether or not people are able to make decisions on a specific matter at a specific time. See Appendix 2.

4.14 At the intersection of all these factors is the question of the extent to which adults should be left by public services to behave in a way that is objectively detrimental to their health and wellbeing or which threatens their lives. More fundamentally it is question of prioritising freedom of choice or prioritising protection from harm (essentially Articles 8 and 2 of the Human Rights Act 1998). The guidance on working with people who self-neglect helpfully challenges the either/ or nature of this question by asking practitioners to consider:

4.15 Is a person who self neglects really autonomous when:

a) They do not see how things could be different
b) They do not think they're worth anything different
c) They did not choose to live this way, but adapted gradually to circumstances
d) Their mental ill-health makes self-motivation difficult
e) They have impairment of executive brain function

4.16 Is a person who self neglects really protected when:

a) Imposed solutions do not recognise the way they make sense of their behaviour
b) Their 'sense of self' is removed along with the risks
c) They have no control and no ownership
d) Their safety comes at the cost of making them miserable

4.17 The extent to which these questions were asked or considered will be examined in Rosey's case.

4.18 In certain circumstances when working with people who self-neglect, it may be appropriate to apply to the Court of Protection for decisions about mental capacity to make a particular decision or deprivation of liberty. It may also be appropriate to use the High Court's inherent jurisdiction. Neither approach, however, is always successful. Using the High Court's inherent jurisdiction is costly and time consuming and as Southend-on-Sea Borough Council found ([2019] EWHC 399 (Fam)), a judgement in support of the application may not confer any additional powers to take action.

4.19 There is also no protocol or agreement on who should lead on these applications, and there is often an expectation that the local authority should do even if it has had little previous involvement. Applications to the Court of Protection should in general be made by the organisation that is best placed to act upon the Court's decision. Court of Protection determinations on, for example, medical treatment in hospital should be applied for by health services.

4.20 **Decisional and Executive Capacity**

4.21 The extent to which a person who self neglects can put whatever decisions they make into effect should also be considered. In Rosey's case there were concerns about her ability to self-care and to accept support. Whilst the Mental Capacity Act does not (currently, but the revised code of practice will, subject to consultation) explicitly recognise the difference between decisional capacity (the ability to make a decision) and executive capacity (the ability to turn that decision into action), it is an important distinction in practice.

4.22 There is also evidence of the impact of both long-term trauma and of schizophrenia on cognitive ability and especially on executive brain function (which includes working memory, mental flexibility, and self-control and regulation) which in turn impacts on mental capacity. Of relevance is that, compared with control groups, people with impaired executive brain function:

- Are significantly slower and less accurate at problem solving when it involves planning ahead.
- Persisted with riskier behaviours for longer and were less responsive to negative outcomes.
- Were no different when identifying what the likely outcome of an event would be.

4.23 Rosey had a form of schizophrenia in which negative symptoms were dominant. Negative symptoms include lack of motivation, social withdrawal, flattened emotions and unwillingness to engage in previously pleasurable activities. They can appear similar to chronic depression and there is a particularly strong relationship between the presence of negative symptoms and impaired cognitive functioning (Correll and Schooler, 2020).

4.24 As a result, people with frontal lobe damage caused by schizophrenia or by traumatic experiences might have the mental capacity to predict what might happen but are less likely to be able to take action to prevent it from happening.

4.25 Significantly, these cognitive deficits are unlikely to be detected using the verbal reasoning tests frequently used in mental capacity assessments. It does not appear that this was considered when decisions about Rosey's mental capacity were made.

4.26 The proposed revised Code of Practice for the Mental Capacity Act will, subject to consultation, include guidance on assessing mental capacity where there is an impairment in executive functioning and a mismatch between what a person says and what they do. The proposed revisions include that, "A person who makes a decision which others consider to be unwise should not be presumed to lack capacity. However, a series of unwise decisions may indicate an inability to use or weigh information" (section 4.39).

4.27 **Care Act assessments**

4.28 In addition to the Mental Capacity Act and the Mental Health Act, practice with adults who self-neglect frequently takes place in the context of the Care Act.

Section 1 of the Care Act (2014) states that, "*The general duty of a local authority, in exercising a function under this Part in the case of an individual, is to promote that individual's well-being*". A definition of wellbeing is provided (see Appendix 3) but for the purposes of this review, it is sufficient to note that wellbeing includes personal dignity (including treatment of the individual with respect); physical and mental health and emotional wellbeing; and the suitability of living accommodation.

4.29 Section 9 of the Care Act (2014) states that where it appears to a local authority that an adult may have needs for care and support, the authority must assess (a) whether the adult does have needs for care and support, and (b) if the adult does, what those needs are.

4.30 This Care Act duty applies regardless of the authority's view of (a) the level of the adult's needs for care and support, or (b) the level of the adult's financial resources.

4.31 Under S19(3), local authorities can meet urgent needs for care in the absence of an assessment.

4.32 There was only one safeguarding enquiry made regarding Rosey and that was after she died. Section 42 of the Care Act sets out the circumstances in which a safeguarding enquiry must be made (see Appendix 3). Safeguarding enquiries and interventions should also be made in such a way that they make safeguarding personal and apply the Six Principles of Adult Safeguarding: Empowerment, Prevention, Proportionality: Protection; Partnership and Accountability (Paragraph 14.13 Care and support statutory guidance).

4.33 **Family involvement, respecting choice and wishes and confidentiality and sharing information**

4.34 The Care Act sets out the wellbeing principle and that, "*the core purpose of adult care and support is to help people to achieve the outcomes that matter to them in their life*". Section 2.18 of the Care and Support Statutory Guidance for the Care Act states that promoting a person's wellbeing, "*should include consideration of the role a person's family or friends can play in helping the person to meet their goals"*.

4.35 During the last few years of her life Rosey was rarely, if at all, in contact with her family. Developing and maintaining family or other personal relationships is included within the Eligibility Regulations for social care: "*Local authorities should consider whether the adult is lonely or isolated, either because their needs prevent them from maintaining the personal relationships they have or because their needs prevent them from developing new relationships*" (s6.106 (g) of the Care and Support Statutory Guidance)

4.36 Consequently, supporting Rosey to renew contact with her family would have been consistent with the duty to promote her wellbeing. Rosey, however, told practitioners not to contact her family members.

4.37 There is a clear legislative expectation that the views of adults with care and support needs are valued and that their choices are respected and followed wherever possible. The Care Act, for example, recognises the importance of "beginning with the assumption that the person is best-placed to judge their situation" and places a duty on local authorities to make sure that:

- The person participates as fully as possible in decisions and is given the information and support necessary to enable them to participate
- decisions are made having regard to all the person's circumstances (and are not based only on their age, appearance or other condition or behaviour)
- any restriction on the person's rights or freedom of action is kept to the minimum necessary.

4.38 Section 1.14 of the Care and Support Statutory Guidance for the Care Act also states that, "*Considering the person's views and wishes is critical to a person-centred system. Local authorities should not ignore or downplay the importance of a person's own opinions in relation to their life and their care. Where particular views, feelings or beliefs (including religious beliefs) impact on the choices that a person may wish to make about their care, these should be taken into account. This is especially important where a person has expressed views in the past, but no longer has capacity to make decisions themselves*".

4.39 Practitioners often face a dilemma when balancing a person's views and wishes with the need to act to protect them from harm. S14.187 of the Care and Support Statutory Guidance for the Care Act states that "…*agencies should reach an agreement about confidentiality and information sharing which is consistent with the Caldicott principles that*:

- information will only be shared on a 'need to know' basis when it is in the interests of the adult
- confidentiality must not be confused with secrecy
- informed consent should be obtained but, if this is not possible and other adults are at risk of abuse or neglect, it may be necessary to override the requirement
- it is inappropriate for agencies to give assurances of absolute confidentiality in cases where there are concerns about abuse, particularly in those situations when other adults may be at risk"

4.40 s14.188 of the Care and Support Statutory Guidance for the Care Act states that, "*Where an adult has refused to consent to information being disclosed for these purposes, then practitioners must consider whether there is an overriding public interest that would justify information sharing (for example, because there is a risk that others are at risk of serious harm) and wherever*

possible, the appropriate Caldicott Guardian should be involved. Confidentiality: NHS Code of Practice sets out guidance on public interest disclosure".

4.41 There was a risk that should Rosey, or another party, complain to the Local Government and Social Care Ombudsman or to the NHS and Parliamentary Ombudsman about contact with her family without her consent, then the Ombudsman might reach a finding of maladministration which might also include a payment of compensation.

4.42 Common law, the Human Rights Act 1998 and the General Data Protection Regulations (GDPR), supplemented by the Data Protection Act 2018, regulate the processing of personal data about living individuals in the UK.

4.43 The GDPR defines personal data as: "*any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person"* and sets out a number of principles covering its use and storage. Essentially, disclosure of confidential information is only allowed if consent to disclose is given, if disclosure is required by law or when it is justified in the public interest.

4.44 If Rosey, or another party, complained about a breach of the GDPR there is risk that this would have resulted in a fine.

4.45 It is unlikely that Rosey's decision to refuse contact with her family posed a risk to other people and that her choices and should therefore be overridden. However, even where there is no public interest concern, practitioners should also consider and assess whether or not a person has the mental capacity to make a decision. In Rosey's case this would have included exploring the reasons why she did not want contact with her family; and determining whether or not she understood, retained and used and weighed the information necessary to deciding that she did not want contact, in addition to her ability to communicate her decision.

4.46 Even if Rosey had made a capacitous decision that there should be no contact with her family, attempts by her family to contact services should not be rejected. The General Medical Council, for example, states that "*In most cases, discussions with those close to the patient will take place with the patient's knowledge and consent. But if someone close to the patient wants to discuss their concerns about the patient's health without involving the patient, you should not refuse to listen to their views or concerns on the grounds of confidentiality. The information they give you might be helpful in your care of the patient*".

4.47 The Royal College of Psychiatrists goes further in suggesting that professionals may initiate contact with others including family members,

stating, "*There is nothing to prevent you, or any other healthcare professional, from receiving information provided by any third party about the patient, as receiving information does not equate to disclosure*. *Indeed, provided the circumstances do not involve disclosure of confidential information, a healthcare professional may actively request information without the patient's consent. This can be an important part of the risk assessment of a patient*".

4.48 Despite this, the GMC strikes of a note of caution and warns that, "*You should, however, consider whether your patient would consider you listening to the views or concerns of others to be a breach of trust, particularly if they have asked you not to listen to specific people. You should also make clear that, while it is not a breach of confidentiality to listen to their concerns, you might need to tell the patient about information you have received from others – for example, if it has influenced your assessment and treatment of the patient. You should also take care not to disclose personal information unintentionally – for example, by confirming or denying the person's perceptions about the patient's health*".

4.49 There is a distinction here between a practitioner disclosing personal data (which includes health information) to a person's family against the person's wishes and receiving information from a person's family. However, Rosey had said that she did not want professionals to contact her family, and Rosey's wishes should have been respected unless it was not in the public interest to do so, or a mental capacity assessment had determined that Rosey lacked the mental capacity to make that decision.

5 ANALYSIS

5.1 Using this research and practice evidence base it is possible to analyse the way in which the different organisations involved worked with Rosey.

5.2 Recognition that Rosey was self-neglecting

5.3 There was a recognition that Rosey was self-neglecting, evidenced on 19/6/19 for example, when Rosey's CPN discussed self-neglect with her and asked Rosey to imagine what her sister would think of this.

5.4 The following paragraphs analyse practice with the guidance on self-neglect referenced in section 4 of this report.

5.5 It appears that more could have been done to *seek to understand the meaning and significance of Rosey's self-neglect, taking account of her life experience.* In 2001 Rosey's family told mental health services that Rosey had not grieved properly after the death of her mother. There is no evidence that the CPNs in 2016 and 2017 and beyond discussed this with Rosey. On 31/12/19 Rosey's CPN wrote that Rosey had spoken a little about her mother. There is no record of this being explored further. Similarly, when in March 2016 Rosey said "If I have cancer, I don't want to know about it" there was no

exploration of why she thought this. Further discussion of the reasons for this decision may have led to a better understanding of why Rosey felt this way.

5.6 In 2016, LPT identified Rosey's increasing "somatic preoccupation": a significant focus on physical health symptoms to a level that results in distress and even to problems in everyday living. LPT considered this to be an indication of Rosey's deteriorating mental health condition, but it could have also been an indication of Rosey's fears about her own physical health in the context of any family history.

5.7 There were some interventions *to communicate about risks and options with honesty and openness.* For example, on 17/6/20 one of the Depot Duty Rota CPNs visited Rosey and noted the unsanitary conditions in her home. The CPN returned two days later with Rosey's regular CPN to see if Rosey was capable of cleaning and tidying with support, to ascertain if Rosey understood the importance of cleanliness, and to prompt and assist Rosey to improve the conditions in her flat. Then in July 2020 Rosey's CPN warned Rosey that her tenancy may be in jeopardy if her flat remained so unkempt and cluttered. This resulted in Rosey tidying up her flat.

5.8 There was evidence of *working patiently at the pace of the individual*: Rosey was not unduly pressured and on occasion *this occurred within the context of knowing when to make the most of moments of motivation to secure changes.* An example of the recognition of a moment of motivation was when, on 28/7/20, the CPN complemented Rosey on tidying her flat and noted that Rosey had beamed with pride. Strengths based approaches, which capitalise on Rosey's skills and achievements, may have helped professionals to engage with her. Despite this, there was evidence that opportunities were not always taken. For example, in 2016 Rosey was referred to a befriending service to relieve her social isolation but the referral was not followed up and the service was not provided.

5.9 ASC has stated that over 70% of referrals it receives result in signposting to other agencies / services and does not have the capacity to follow all of these up. There may be a need for a more nuanced approach to follow up, on a case-by-case basis. Rosey lived on her own and had little contact with her family and friends, she had no one on a more personal level to motivate and remind her to do things. Practitioners should have considered whether Rosey would initiate contact with the befriending service or remain able to self-care and whether a more assertive and persuasive approach was needed to secure Rosey's engagement with the befriending service.

5.10 **Multi-agency working with Rosey**

5.11 There were some attempts at *proactive work to engage and co-ordinate agencies with specialist expertise to contribute towards shared goals*, but these fell at the first hurdle. For example, after 2016 Rosey's regular CPN suggested further care and support assessments, but because Rosey would not agree to this, ASC was never approached. This may have been an opportunity for a multi-agency discussion about Rosey's needs and for

problem solving and consideration of other interventions. In January 2020 a healthcare support worker (HCSW) visited Rosey with Rosey's regular CPN to take a blood test. Subsequently the CPN suggested to Rosey that she consider support from a HCSW to re-establish a routine, accessing social activities, building up confidence in walking to the chemist and to help with her anxiety. Rosey declined this on the basis that the HCSW may be too overpowering and would upset her.

5.12 There were a number of missed opportunities to escalate concerns and draw in other agencies to consider alternative interventions. For example, in March 2019 there appears to have been a change in Rosey's self-care in that her dressing gown was damp with urine, which did not seem to concern Rosey. Rosey refused to go out in the community, lead a healthier lifestyle or to improve her self-care. In April 2019 Rosey was recorded to have smelt odorous and as the most unkempt her CPN had seen her since 2017. Consideration could have been given to a referral for adult social care and/or occupational therapy at this time.

5.13 On 19/6/19 Rosey would not allow the CPN access to her home. The CPN raised her increasing concerns about Rosey at the CMHT's multi-disciplinary team meeting. This was not escalated any further as it was felt that pressuring Rosey or raising concerns with other agencies would lead Rosey to disengage with services.

5.14 On 17/6/20 and 19/6/20, CPN visits to Rosey found rotting rubbish and flies in her flat, and Rosey was described as unwashed, smelling of body odour and wearing dirty pyjamas. No safeguarding adults referral for self-neglect was made, nor was Environmental Health or LCC Housing contacted to seek advice about the condition of Rosey's flat.

5.15 In summary there was insufficient escalation and sharing of information with other professionals to work towards shared goals and to influence outcomes for Rosey.

5.16 **Legal powers and duties and understanding Rosey's mental capacity to make decisions**

5.17 Rosey's mental capacity was not fully assessed. Consequently, more could have been done to have kept *constantly in view the question of the individual's mental capacity to make self-care decisions*. Fuller attention to assessing Rosey's mental capacity may have resulted in professionals coming to different conclusions about Rosey's ability to care for herself or to refuse contact with her family and may ultimately have achieved better outcomes for her. Conversely, had mental capacity assessments determined that Rosey did have mental capacity in these areas, they would have been documented and risk assessed and could have demonstrated defensible decision making.

5.18 There did not appear to be sufficient consideration of *options for intervention and to ensure these were rooted in a sound understanding of legal powers*

and duties. The options that were considered were a Mental Health Act assessment, which was not carried out because it was felt that Rosey was on the border of, but not beyond the criteria for being detained under a section of the Act. Practitioners also commented that people are not detained under the Mental Health Act for self-neglect. The option to make a safeguarding referral was dismissed on the basis that it would risk Rosey disengaging with services. Apart from a care and support needs assessment (see below) where Rosey was assessed to be able to understand and retain information and was noted to have held a coherent discussion about the assessment, no other Mental Capacity Act (MCA) assessments were not made. Rosey was assumed to have mental capacity on the basis that she had once cleaned up her flat when she was warned that a cluttered flat could jeopardise her housing tenancy. This indicates insufficient understanding of the MCA and how mental capacity may vary over time and how someone may be capacitous to make certain decisions but not for others. Practitioners were concerned at the time that asking Rosey to undertake a mental capacity assessment may have resulted in her refusing her medication. Practitioners noted during this review that a delicate balancing act was necessary in deciding on action and that this was not uncommon in cases of self-neglect. Practitioners feared that if they pushed Rosey too far then she would disengage with them. If, however, Rosey had been assessed to lack the mental capacity to care for herself then this would have required that actions were taken to meet Rosey's needs in her best interests.

5.19 Consideration does not appear to have been given to how Rosey's mental health may have affected her capacity to make decisions. Rosey's schizophrenia may have meant that she had an impairment or disturbance in the functioning of her mind or brain (the three-part mental capacity test is set out in Appendix 2) and decisions Rosey made about, for example, her ability to look after herself or to refuse access to her flat might have been tested to ensure that they were capacitous.

5.20 Even if Rosey appeared to be able to understand, retain and use or weigh information relevant to decisions and to be able to communicate her decisions, it does not mean that these should have been left unchallenged. All public sector bodies, whether or they are directly or indirectly funded by the UK Government have a duty under the Human Rights Act to discharge the State's positive obligations under the European Convention on Human Rights. These include Article 2 to protect life and Article 8 to protect the right to respect for private and family life (autonomy). Practitioners need to balance the need to protect life with the need to protect autonomy. In Rosey's case this would have included balancing interventions to meet Rosey's physical and mental health needs between 27/10/20 and 10/11/20 when no contact was made with her, with respecting Rosey's freedom of choice and private and family life. This can be a difficult balance to strike but the duty to protect life may override the duty to protect autonomy and should be considered with reference to the person's previous choices, preferences and decisions and with compassionate regard for the implications of overruling them.

5.21 Instead, the approach taken was to work with Rosey consensually, to visit her at a time when she was expecting to receive her depot injection when it was hoped that she would allow access to her home. Nurses state that a special "knock" on the door was used, signalling to Rosey that it was a medication visits. Whilst practitioners worked at Rosey's own pace, this approach led to a delay in assessing and responding to concerns raised in the PPN about Rosey's welfare. A more rapid response to these concerns, prioritising the need to protect Rosey who had not been seen since 21/10/20 was required but was not made. The delay was finally resolved, after fourteen days had passed since the last contact with Rosey, by the AMHP who decided on a more assertive course of action, prioritising the protection of Rosey on 11/11/20.

5.22 **Engagement with Rosey's family members**

5.23 Engagement with Rosey's family should be understood in the context of what was once a very happy sibling relationship, but which, to the regret and upset of Rosey's brothers and sisters, changed dramatically following the death of their mother. Rosey began to mistrust her family, and one by one Rosey began to reject help from them and saw them as interfering. Rosey's family recounted that Rosey once threatened one of her sisters with a knife. The advice Rosey's family received following this was to restrain Rosey and not allow her to go out. This led to further deterioration in their relationship with Rosey.

5.24 It was against this background that Rosey told practitioners that she did not want them to contact her family about her, although it is unclear when Rosey made this request.

5.25 The GP practice knew that Rosey had a sister who had previously supported her and had contacted Rosey's family when Rosey had relapses in 2010 and 2012. According to the practice, however, as Rosey had not attended the surgery in the latter years of her life, they did not contact her family again.

5.26 ASC had two of Rosey's sisters recorded as emergency contacts for her but there had been no contact with them. Following the PPN on 20/10/20, ASC contacted Rosey's CPNs. Rosey's regular CPN said that they had no concerns about Rosey's mental capacity and this was ASC's rationale for not contacting Rosey's sisters before visiting Rosey at home. ASC believed that Rosey was opposed to her family being contacted by professionals about her. It was not until Rosey was admitted to hospital that contact was made with her sisters.

5.27 The question arises of whether practitioners could have worked more closely with Rosey's family in making decisions about how best to support Rosey. The law and guidance around disclosure of personal data and contact with family members is summarised in section 4. Whilst there is a difference between practitioners receiving information from family members and disclosing confidential information to family members, there is a clear legislative expectation that the views of adults with care and support needs

are valued and that their choices are respected and followed wherever possible. Whilst practitioners stated that Rosey did not want them to contact her family, it is unclear when Rosey expressed this wish. For example, in 2008, Rosey's sister had been consulted as part of a Care Programme Approach (CPA) assessment and gave insight into Rosey's life and personality prior to her mother's death. In March/ April 2016 Rosey's CPN contacted Rosey's sister when Rosey did not attend for her depot injection.

5.28 The care and support needs assessment in July 2016 recorded that Rosey's two sisters visited her once a month to support with delivering large, heavy grocery items. It is not clear whether the background information supplied by Rosey's sister during the CPA assessment in 2008 was used in the care and support needs assessment and practitioners did not appear to have considered approaching Rosey's family to help inform the care assessment, nor do they appear to have asked Rosey whether they could contact her family as part of the care assessment. There appears nothing to indicate that Rosey had refused family contact at this time, so there was potential for the CPN and / or the ASC assessor to have asked Rosey again and to have explored contact with her family rather than have accepted that her previous position on contact was still current. Rosey's family could have been asked about how Rosey was before she experienced mental ill health.

5.29 According to her family Rosey was a vibrant individual, she was attractive, had long blond hair, took pride in her appearance and "turned heads" as she walked down the street. However, by 2016 her hair was matted, and she was no longer caring for herself to a standard that she used to maintain or that was even generally socially acceptable. Awareness of Rosey's history could have helped practitioners to compare her current presentation and circumstances with those of her former self. This might help to avoid the risk of normalisation, in which a person's current presentation and circumstances are considered to be their "natural'' state when in fact they represent a significant change. People who self-neglect should not be compared with others who self-neglect but with themselves before they self-neglected and this is an opportunity for practitioners to consider the questions set out in section 4.15 and to ask, for example, whether Rosey had chosen to live this way or had adapted gradually to her circumstances.

5.30 When Rosey did express her wish for her family not to be contacted practitioners could have explored the reasons for her reluctance further. They could have undertaken a mental capacity assessment to determine whether Rosey had the capacity to refuse practitioner contact with her family. Fuller attention to mental capacity may have resulted in different conclusions by professionals, or if they had concluded that Rosey had the mental capacity to refuse contact with her family, the reasons for complying with Rosey's wishes would have been more defensible.

5.31 Rosey was diagnosed with schizophrenia and at times had expressed some delusional beliefs. It is not inconceivable that her mental health needs have influenced her beliefs about her about her family too, which had led her to not want them to visit her and to prohibit practitioner contact with them.

Consideration could have been given to how the relationship with her family could have been improved, through counselling or other therapeutic interventions.

5.32 Practitioners appeared to accept Rosey's rejection of her family as her wish, without challenging Rosey's rationale. A *more flexible and innovative approach may have achieved more positive relationships and greater involvement of family members in contributing to interventions.*

5.33 **Consideration of an advocate for Rosey**

5.34 More could have been done to consider *how community resources could contribute to interventions.* In light of Rosey's mistrust of her family and of practitioners, seeking an *advocate* for Rosey may have provided Rosey with someone she could trust and confide in. This may have helped to better understanding Rosey's fears and motivations and her expectations from services.

5.35 In summary, it was recognised that Rosey was self-neglecting and there were some approaches made by practitioners which were consistent with the self-neglect guidance listed in section 4. Future practice could be improved by considering *life history and the significance and reasons for self-neglect, making the most of moments of motivation, legal literacy, multiagency working, use of community resources and flexible thinking in engaging with family members.*

5.36 **Care Act Assessments**

5.37 In June 2016 Rosey's CPN observed that Rosey's self-care was poor, she was not motivated to get dressed or open the curtains or go food shopping. How Rosey obtained food is not noted. In July 2016 Rosey agreed to have an assessment of her care and support needs. It is not known why one had not been requested or undertaken before this time. The assessment was made by ASC jointly with Rosey's CPN. During the assessment Rosey revealed that she had not washed her hair for four months, nor had she done any washing and so had no clean clothes or bed sheets.

5.38 The assessment found that Rosey did not have care and support needs as she was independent in all daily living activities, but a private cleaner was suggested.

5.39 Under the Care and Support (Eligibility Criteria) Regulations 2014 (See appendix 4), the circumstances in which someone might be eligible for care and support are that they have a physical or mental impairment or illness and cannot achieve any two of ten outcomes which include maintaining and managing nutrition, being appropriately clothed, being able to maintain a habitable home environment, using facilities in the local community and maintaining family and personal relationships. There appears to have been a lack of recognition that although Rosey was physically capable of washing and dressing herself and of washing clothes and bed linen, her mental health

condition or other factors might have prevented her from doing this. However, ASC state that Rosey said that she was able to manage tasks, acknowledged things had slipped but that she was intending to pick up aspects (such as personal and domestic hygiene). Rosey was judged to be able to understand and retain information and was reported to have held a coherent discussion about the assessment domains. The only (single) Care Act domain ASC found Rosey needed support was with social connections / accessing the community.

5.40 Rosey's CPN was not notified of the outcome of the assessment for seven months and did not enquire what the outcome was during this time.

5.41 Rosey continued to self-neglect and rejected any further offers of an assessment of her care and support needs. Rosey's family believe that the assessment in 2016 passed ASC's responsibilities to meet Rosey's care and support needs under the Care Act to LPT.

5.42 A mental capacity assessment could have been undertaken to determine whether Rosey had the capacity to refuse further care assessments. If it was found that she lacked capacity a Best Interests decision could have been taken to conduct one. If the assessment found that she had care and support needs, a multi-agency approach to how to meet these in a way that was acceptable to Rosey, could have been used to secure a better outcome.

5.43 **Handling of safeguarding and consideration of the Vulnerable Adults Risk Management process.**

5.44 No safeguarding concerns had been raised about Rosey until after her death. On 27/10/20, following the PPN on 20/10/20, Rosey's CPN and a social worker discussed the use of the safeguarding process or the Vulnerable Adults Risk Management (VARM) process as possible responses to Rosey's self-neglect. No progress with either of these options appears to have been made but Rosey's CPN was advised to contact the Adult Mental Health Central Social Work team, and it appears that ASC initiated the action themselves to transfer Rosey to this team, which was good practice.

5.45 A visit to the wrong address was made on 30/10/20, which was not realised until 10/11/20 when a social worker accompanied Rosey's CPN to the correct address on a visit to administer Rosey's next depot injection. On no response, the CPN and the social worker visited separately the next day and having again received no response, the CPN referred Rosey for an AMPH assessment. The AMPH arranged for police support to issue a s135(1) warrant under the Mental Health Act and Rosey was taken to hospital where she died on 24/11/20.

5.46 There were a number of occasions when raising a safeguarding concern may have been appropriate. These include when, in the spring of 2019, Rosey became increasingly unkempt and her clothes smelt of urine, and particularly in May and June 2020 when flies and rotting rubbish were found in her flat and Rosey was noted to be dressed in dirty clothes. The threshold for raising

a safeguarding concern is low and it is the duty of local authorities to decide on the necessary actions. Referrers should not be dissuaded from raising concerns because they may not meet the criteria set out in s42 of the Care Act.

5.47 LPT practitioners, however, felt that if they had raised Rosey's case as a safeguarding concern it would have risked Rosey disengaging from services. Rosey's unhygienic living conditions may have put her health at risk (irrespective of cancer) and fears about disengagement could have been discussed with ASC when raising a safeguarding concern earlier.

5.48 The safeguarding enquiry after Rosey's death appears to have been triggered by a request from the coroner and scrutiny by more senior staff in ASC. The delay has been ascribed to the priority given for the AMHP to assess Rosey on 11/10/20 and then the subsequent focus on Rosey's health condition. However, ASC are clear that a safeguarding enquiry should have been opened in a more timely way, when the concerns surrounding Rosey's situation on 11/11/20 were evident**.**

5.49 Practitioners felt that work to promote the role of AMHPs in identifying and reporting safeguarding adult concerns would be useful. Safeguarding Core Training has now been offered and provided to the majority of frontline AMHPs in ASC.

5.50 However, at this stage, after Rosey's death, it was difficult to apply the six principles of safeguarding: *empowerment, prevention, protection, proportionality, partnership and accountability*. The enquiries could not prevent further harm to Rosey, nor protect her. Rosey could not be *empowered* to say what she wanted, nor could the person leading the enquiry have *accounted* to Rosey for their actions. Instead, Rosey's family could have been involved but that does not appear to have happened.

5.51 The VARM process was also not considered by practitioners before the PPN on 20/10/20. The VARM guidance provides front line practitioners with a multi-agency framework which facilitates effective working with adults who are at risk due to self-neglect, where that risk may lead to significant harm or death if nothing in that person's situation changes. https://www.llradultsafeguarding.co.uk/varm/

5.52 The VARM process could have been an effective way to share information on a multi-agency basis without the need for Rosey's consent. It is unknown whether Rosey would have been considered at risk of serious harm or death, because, prior to her admission to hospital in November 2020, Rosey's cancer was undetected.

5.53 It appears that LPT staff had not been trained in safeguarding to the level required by the intercollegiate document Adult Safeguarding: Roles and Competencies for Health Care Staff which was published in 2018 https://www.rcn.org.uk/professional-development/publications/pub-007069. Some of the training provided did not include self-neglect.

5.54 According to LPT, there were no effective internal policies, procedures, training, accessible advice and awareness raising processes in place for frontline staff to have understood and implemented safeguarding response to self-neglect. At the time of writing this SAR, LPT's safeguarding team now have a quality improvement programme in place to ensure that adult safeguarding training is provided to all frontline clinical staff in accordance with the intercollegiate document.

5.55 **Consideration of Rosey's mental health needs and treatment**

5.56 Rosey was administered anti-psychotic medication, which according to practitioners she accepted and believed helped her.

5.57 However, depression and anxiety also featured in Rosey's life. Following the death of her mother in 2000, Rosey was prescribed anti-depressants by her GP but did not take them.

5.58 In June 2016 Rosey displayed "negative" symptoms of psychosis such as lack of motivation culminating in poor self-care, disengagement from her family and clinical staff, and lack of engagement in social activity. As a result, Rosey's CPN increased her anti-psychotic medication in liaison with a psychiatrist. The records do not indicate any consideration of any additional diagnosis such as a depressive illness, despite the symptoms being similar. In July 2019 Rosey's psychiatrist considered that an anti-depressant may assist with Rosey's negative symptoms and a Mental Health Act assessment was considered. Rosey rejected the idea of anti-depressant medication saying that she was fine and a MHA assessment was not undertaken. In hindsight, practitioners felt that generally people were not detained under the Mental Health Act for self-neglect.

5.59 In June 2017 Rosey presented with social anxiety and her anti-psychotic medication was increased again. There does not seem to have been any exploration or consideration of therapeutic interventions to manage anxiety, such as Cognitive Behavioural Therapy. A further intervention was made in December 2019, about two and a half years later, when Rosey mentioned her anxieties to her CPN. According to LPT, Rosey's CPN responded appropriately with anxiety management techniques, the option of medication and a "collaborative care plan".

5.60 Other interventions such as occupational therapy and assertive outreach teams were not considered. By 2009 services for people with psychotic illnesses were in place including Early Intervention in Psychosis, Crisis Resolution and Home Treatment and Assertive Outreach (AOT) services. AOT services were implemented nationally in 2001 as a model to work assertively and intensively with people who did not engage well with traditional mental health services and had a serious mental illness.

5.61 In summary Rosey's mental health needs were responded to with a focus on anti-psychotic medication. However, anxiety and depression also featured in

Rosey's life, but Rosey seemed not to recognise that she was depressed and refused to take anti-depressants, and too little consideration appears to have been given to alternative therapeutic interventions. These may have changed Rosey's view of herself and perhaps reduced her self-neglect, improved her motivation, and may have enabled her to report physical health concerns.

5.62 **NICE Guidance on Improving Physical Health and annual metabolic monitoring [CG178].**

5.63 Evidence shows that people with serious mental illness die up to 20 years younger than the general population. https://www.nice.org.uk/sharedlearning/improving-physical-health-for-people-with-serious-mental-illness-smi. This may be because people with psychosis or schizophrenia often have physical health problems, including cardiovascular and metabolic disorders, such as type 2 diabetes, which can be exacerbated by the use of antipsychotic medication.

5.64 Rosey's GP practice invites all patients on the Serious Mental Illness register for an annual physical health check. These are performed by a Mental Health Facilitator employed by LPT, who reviews each person's physical health including their blood pressure and weight and takes blood tests. Rosey was invited for these reviews but did not attend. There does not appear to have been more assertive follow up after non-attendance.

5.65 Despite this, Rosey's annual metabolic monitoring necessary for her continued use of antipsychotic medication continued. This was up to date in March 2020 and Rosey's metabolic blood test results were normal and did not raise any concerns. However, in some previous years, such as 2016, there was no record that tests had been done.

5.66 **Rosey's treatment, health monitoring and timing of the detection of breast cancer**

5.67 The breast screening service sends an invitation and, if necessary, two reminders to women from the age of 50 years old for breast screening. This is repeated every 3 years and women can book themselves in for screening before the next 3-year review if needed. The screening results are sent to the GP practice.

5.68 Rosey was invited for mammograms on 29/12/14 and 7/11/17 which she did not attend. The next expected routine mammogram would have been around December 2020 (after her death) but this may have been delayed due to the Covid pandemic backlog. Rosey also did not attend any other screening appointments during that time.

5.69 According to Rosey's GP, even if the appointment in 2017 had been attended, it is unlikely the screening would have picked up the cancer she died from, unless it was a particularly slow growing tumour.

5.70 Rosey's patient records were flagged to indicate that she had not attended appointments, so that this could be discussed with her if she attended the GP practice. Missed appointments were also usually discussed at the annual physical health check for patients on the Serious Mental Illness register. At the time of writing this SAR, there is a national drive to improve the uptake of all screening in certain population groups (such as patients with learning disabilities or patients from ethnic minorities where there is low uptake). Rosey's GP practice is expanding the support offered to patients from vulnerable groups to increased attendance for screening. The practice is exploring whether newly appointed social prescribers and health and wellbeing coaches employed by Primary Care Networks could assist in this, but they were not in place when Rosey may have benefitted from them.

5.71 The national 3-year timescale for breast cancer screening may be insufficient for people with mental health needs and who do not have intimate partners.

5.72 **Medical records**

5.73 Rosey's family have reported that when Rosey was admitted to hospital, hospital staff were prevented from obtaining Rosey's mental health records. Any information sharing concerns that currently prevent this should be resolved.

5.74 **The role of Leicester City Council housing department**

5.75 Rosey held a council tenancy from 2002 with LCC. LCC Housing operatives attend council properties to carry out repairs and gas servicing. LCC Housing operatives can generate an alert if they identify welfare issues and these lead to a welfare call. Operatives had entered Rosey's flat seven times between October 2017 and November 2020, when they entered Rosey's flat to repair her boiler. No major issues or concerns raised by the operative.

5.76 This is surprising since the police had entered the property on 20/10/20 and had submitted a PPN describing the property as an "extremely unclean and unhealthy flat' which was "dark and dingy with plaster hanging off the walls". Officers checked all rooms to determine the suitability of the living conditions, identifying that the refrigerator did not work, foodstuffs were covered in mould and Rosey's clothes were stained, with her hair matted.

5.77 LCC Housing identify a cohort of people to welfare check by interrogating their own systems to establish if they have been previously homeless, have ASC involvement, are disabled, or are an older person, or "other such vulnerabilities". This will not necessarily include people with mental health needs, particularly if they are not known to ASC. The welfare checks involve contacting the tenant to see if they need support. People with serious and prolonged mental health needs, like Rosey, are likely to be "vulnerable" and should be included within the cohort identified by LCC Housing and any information sharing concerns that currently prevent this should be resolved.

5.78 There had also been no contact by ASC, LPT or the police with LCC Housing to raise any concerns about Rosey or her living conditions and to increase her profile as a vulnerable tenant.

5.79 **Good Practice**

5.80 CPNs continued to visit Rosey during the lock-down which started in March 2020 in response to the Covid-19 pandemic. This ensured Rosey continued to be treated with her anti-psychotic medication and ensured some social contact, given that she was isolated.

5.81 The Police took appropriate action on 20/10/20 in referring to ASC and issuing a PPN.

5.82 The AMHP recognised the need for an assertive intervention on 11/11/20 since there had been no contact with Rosey since 21/10/20 and the police recognised the need to force entry into Rosey's home.

6. CONCLUSIONS

6.1 Working with people who self-neglect

6.2 Rosey was recognised as self-neglecting, and some approaches made by practitioners were consistent with the self-neglect guidance set out in section 4 of this report.

6.3 Despite this the extent of Rosey's self-neglect was not recognised. After Rosey was found on the floor on 11/11/20 her family members took photographs which showed that Rosey's toe nails were overgrown, her breast tissue was necrotic with a significant open wound, her bathroom was ingrained with dirt and faecal matter and clutter made the bath inaccessible. Rosey's mattress and living furniture has springs showing and had been wet. Rosey's living areas were unhygienic and her fridge contained mould and was dirty. It is surprising that this had not raised significant concerns before and prompted more assertive action. Consequently, Rosey was left in a state of neglect.

6.4 Future practice could be improved by considering *life history and the significance and reasons for self-neglect, making the most of moments of motivation, legal literacy, multiagency working, use of community resources and flexible thinking in engaging with family members.*

6.5 There was inter-agency coordination, but opportunities for escalation and joint working were not always taken

6.6 Whilst there was evidence of some joint working between ASC and LPT, there were a number of missed opportunities to escalate concerns and to consider alternative approaches and interventions. There appears to be a need to

improve information sharing between mental health services and the acute hospital and LCC housing.

6.7 Prior to Rosey's death no safeguarding concerns were raised and the Vulnerable Adults Risk Management (VARM) process was not used. Whilst Rosey's CPN did raise increasing concerns to the CMHT's multi-disciplinary team, this was not escalated any further as it was felt that pressuring Rosey or raising concerns with other agencies would lead Rosey to disengage with services.

6.8 There were, however, occasions when raising a safeguarding concern would have been appropriate. Rosey's unhygienic living conditions were potentially putting her health at risk and fears about disengagement could have been discussed with ASC.

6.9 The safeguarding enquiry was made after Rosey's death by ASC and therefore could not make safeguarding personal or apply the six principles of adult safeguarding. Neither Rosey's family nor an advocate were involved as a representative on Rosey's behalf.

6.10 Following receipt of the PPN the approach taken was to work with Rosey consensually, to visit her at a time when she was expecting to receive her depot injection when it was hoped that she would allow access to her home. This approach led to a delay in assessing and responding to concerns raised in the PPN about Rosey's welfare. A more rapid response to these concerns, prioritising the duty to protect Rosey, who had not been seen since 21/10/20, was required but was not made.

6.11 There was insufficient attention to Rosey's mental capacity and its interface with Rosey's physical and mental health needs.

6.12 Apart from an assessment of mental capacity during the care and support needs assessment in July 2016, Rosey's mental capacity was assumed rather than fully assessed and Rosey's self-neglect appears to have been accepted as a capacitous decision and as a lifestyle choice. Rosey's mental capacity should have been assessed in the context of her self-neglect (as highlighted in the Mental Capacity Act code of practice). More attention should have been given to whether or not Rosey was able to understand, retain and use and weigh the information relevant in, for example, making decisions to refuse an assessment of needs after July 2016 or to not attend to her personal care. Attention also could have been given to Rosey's executive capacity and functioning, particularly about her personal care.

6.13 It is likely that Rosey's mental health needs meant that she had an impairment of, or disturbance in the functioning of her mind or brain and there may have been a "causative nexus" between this and Rosey's decision making. The predominantly negative symptoms of schizophrenia that Rosey experienced may have reduced her motivation, increased her isolation, reduced her interest in activities and impaired her cognitive abilities. Rosey also appears to have lacked insight into her mental health needs and social anxiety. The

effects of schizophrenia and lack of insight should have been considered when assessing the extent to which Rosey could use and weigh relevant information.

6.14 The Mental Capacity Act is clear that capacity must be presumed but (as the proposed revised code of practice states), it may be necessary to consider whether a person has capacity to make a specific decision if:

- The decision the person is proposing to take is significantly out of character;
- The decision the person is proposing to take appears to be unwise, especially if they are putting either themselves or others at risk;
- It has already been shown that the person lacks capacity to make other decisions in their life as a result of an impairment or disturbance that affects the way their mind or brain works;
- A deprivation of the person's liberty is necessary for the person's care or treatment.

6.15 There is also an important distinction between "presumption", a belief based on evidence, and "assumption", a belief held without evidence. The presumption of capacity means that practitioners should keep the question of whether or not a person has the mental capacity to make a specific decision at a specific time in their minds. The proposed revised code of practice for the Mental Capacity Act provides guidance on the circumstances that might lead to a concern that someone may lack the mental capacity to make a decision and identifies that considering a person's capacity is not the same as assessing their capacity.

6.16 Considering means asking whether there is a proper reason to doubt that the person has the capacity to make the decision in question and the proposed code of practice warns that failure to consider this can be just as harmful for the person as an overly hasty decision that they lack capacity to make the decision.

6.17 Causes of concern that may prompt consideration of mental capacity include repeatedly making decisions that appear unwise and present a significant risk of harm or exploitation or making a particular unwise decision that is obviously irrational or out of character.

6.18 These do not necessarily mean that somebody lacks capacity, since people have a right to make decisions that others may feel are unwise, but they might present a need for further investigation, taking into account the person's past decisions and choices, in, for example, the following situations:

- Has the person developed a medical condition or disorder that is affecting their capacity to make particular decisions?
- Are they easily influenced by undue pressure?
- Might someone be influencing or coercing and controlling them?

- Does the person need more information or support to help them understand the consequences of the decision they are facing?

6.19 If there is a proper reason to doubt that the person has capacity to make the decision, it will be necessary to assess their capacity by applying the test in the Act.

6.20 Even if Rosey's refusal of a needs assessment was considered to be capacitous there still may have been sufficient concerns about her safety to have acted to protect her and for example tried to put support in place under s19(3) of the Care Act.

6.21 Rosey's mental health needs were responded to with a focus on anti-psychotic medication. However, anxiety and depression also featured in Rosey's life, but Rosey seemed not to recognise that she was depressed and refused to take anti-depressants. Little consideration was given to therapeutic interventions. These may have changed Rosey's view of herself and perhaps reduced her self-neglect, improved her motivation, and may have enabled her to report physical health concerns.

6.22 NICE Guidance on Improving Physical Health was implemented by Rosey's GP, but Rosey declined annual health checks. However annual metabolic monitoring as per NICE Guideline [CG178] was led by Rosey's CPN and was up to date in 2020.

6.23 Rosey's care and support needs

6.24 There was a lack of recognition during the assessment of Rosey's care and support needs in 2016 that although Rosey said that she would, and was physically able to, wash and dress herself and wash clothes and bed linen, her mental health condition may have caused her not to do this.

6.25 **There was a lack of involvement with Rosey's family**

6.26 Rosey's wish to not involve her family was respected in accordance and guidance and law but was not considered within the context of her mental health needs or her mental capacity. According to Rosey's family, relationships had been good but deteriorated as Rosey's mental health declined.

7. RECOMMENDATIONS

The following recommendations are made at an individual practice, an intra- and inter-agency and a board level. The LSAB should create and monitor a multi-agency action plan to implement to implement them.

7.1 LSAB partner agencies should ensure that there is a process for deciding on which organisation takes the lead on applications to the Court of Protection based on which organisation will be able to apply the Court's determination.

7.2 ASC, LPT and Environmental Health should agree methods to raise multi-agency awareness of, and processes for, using legislation (Care Act, Mental Capacity Act, Human Rights Act, Mental Health Act, environmental health acts etc) to intervene in a timely way to support people who self-neglect and the circumstances and risks which exceed the capability of a single agency, team or individual to manage them on their own and when there is a need to involve other agencies or teams.

7.3 LSAB partner agencies should agree a multi-agency action plan to increase understanding and recognition of self-neglect (including ways of working with people who self-neglect as outlined in this SAR and that self-neglect can be reported as a safeguarding concern). An audit tool should be used across the LSAB agencies to demonstrate that improvements have been made.

7.4 The VARM guidance should be revised so that the connections between it and adult safeguarding are clear and that action to visit urgently in response to concerns is prioritised over consideration of which process to use and that assertive responses under the duty to protect life are focused on. The use of the clutter rating scale to support and communication about and assessment of the level of hoarding should also be emphasised.

7.5 LSAB partner agencies should agree a multi-agency action plan aimed at improving the understanding of the practical application of the Mental Capacity Act (i.e. that it requires assessment rather that assertion, that physical and mental health conditions may mean there is an impairment or disturbance in the functioning of the mind or brain, that mental capacity is decision and time-specific, yet should be seen as a video rather than a snapshot, that the Mental Capacity Act does not give the right to make unwise decisions, linkage to self-neglect, use and weighing a decision and executive functioning, etc). An audit tool should be used across the partnership to demonstrate that improvements have been made.

7.6 ASC should invite representatives from LPT to its monthly multi-agency meetings.

7.7 The LSAB should lead an analysis of the extent to which the policy, procedural and organisational environment in Leicester fosters effective ways of working with people who self-neglect and ask:

- Do agencies share definitions and understandings of self-neglect?
- Is inter-agency coordination and shared risk-management facilitated by clear referral routes, communication and decision-making systems?
- Is longer-term supportive, relationship-based involvement accepted as a pattern of work

- Does training and supervision challenge and support practitioners to engage with the ethical challenges, legal options, skills and emotions involved in self-neglect practice?
- When services withdraw is there sufficient risk management planning to identify and act upon any self-neglect relapse?

7.8 ASC should assure itself that safeguarding enquiries are made in a timely manner and, whether the enquiries are made by ASC or delegated to another agency, that they are made with regard to Making Safeguarding Personal.

7.9 LPT's safeguarding team should work to ensure that specialist interventions such as Assertive Outreach and Occupational Therapy are considered for people experiencing social isolation due to anxiety or negative symptoms of psychosis, lack of occupation and low levels of engagement.

7.10 Where a self-neglecting individual directs agencies not to contact their family and to exclude them from involvement in their care and support, their mental capacity to make this decision should be assessed.

7.11 All partner agencies should be sensitive and responsive to the information needs of bereaved families in situations where a relative with care and support needs has died.

7.12 Ensure that the current shared care agreement with LLR General Practitioners is reviewed and updated as per NICE Quality Standard [QS80], aligning to NICE Clinical guideline [CG178], so that patients with schizophrenia and psychosis whose engagement with services is sporadic or poor, have an agreed care plan as to who and how physical healthcare monitoring will occur annually between LPT and GP's.

7.13 When people who self-neglect, have mental health needs and live alone do not attend health screening appointments, then whichever practitioner is working with them should encourage attendance and liaise with, for example. the person's GP.

7.14 GP practices should follow through on proposals to ensure active follow up of patients who do not respond to invitations for health monitoring, for example, breast cancer screening, to explore barriers and encourage greater take up.

APPENDIX 1: HUMAN RIGHTS ACT

All public sector bodies, whether or they are directly or indirectly funded by the UK Government have a duty under the Human Rights Act to discharge the State's positive obligations under the European Convention on Human Rights:

- Article 2 – to protect life
- Article 3 – to protect against torture, inhuman or degrading treatment
- Article 5 – to protect against unlawful interferences with liberty, including by private individuals
- Article 8 – to protect physical and moral integrity of the individual (especially, but not exclusively) from the acts of other persons

APPENDIX 2: MENTAL CAPACITY ACT

The Mental Capacity Act requires a three-stage test of capacity to make decisions:

1. Is the person unable to make the decision? i.e. are they unable to do at least one of the following things:
   - Understand information about the decision to be made, or
   - Retain that information in their mind, or
   - Use or weigh that information as part of the decision-making process, or
   - Communicate their decision (by talking, using sign language or any other means)

2. Does the person have an impairment of, or a disturbance in the functioning of, their mind or brain, whether as a result of a condition, illness, or external factors such as alcohol or drug use?

3. Does the impairment or disturbance mean the individual is unable to make a specific decision when they need to? Individuals can lack capacity to make some decisions but have capacity to make others, so it is vital to consider whether the individual lacks capacity to make a specific decision at a specific time.

APPENDIX 3: SECTION 42 CARE ACT:

Enquiry by local authority

1) This section applies where a local authority has reasonable cause to suspect that an adult in its area (whether or not ordinarily resident there):

   (a) has needs for care and support (whether or not the authority is meeting any of those needs),
   (b) is experiencing, or is at risk of, abuse or neglect, and
   (c) as a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it.

2) The local authority must make (or cause to be made) whatever enquiries it thinks necessary to enable it to decide whether any action should be taken in

the adult's case (whether under this Part or otherwise) and, if so, what and by whom.

3) "Abuse" includes financial abuse; and for that purpose "financial abuse" includes:

(a) having money or other property stolen,
(b) being defrauded,
(c) being put under pressure in relation to money or other property, and
(d) having money or other property misused.

APPENDIX 4: CARE AND SUPPORT (ELIGIBILITY CRITERIA) REGULATIONS 2014

Needs which meet the eligibility criteria: adults who need care and support

An adult's needs meet the eligibility criteria if:

a) the adult's needs arise from or are related to a physical or mental impairment or illness;
b) as a result of the adult's needs the adult is unable to achieve two or more of the outcomes specified in paragraph (2); and
c) as a consequence there is, or is likely to be, a significant impact on the adult's well-being.

Paragraph 2: The specified outcomes are:

(d) managing and maintaining nutrition;
(e) maintaining personal hygiene;
(f) managing toilet needs;
(g) being appropriately clothed;
(h) being able to make use of the adult's home safely;
(i) maintaining a habitable home environment;
(j) developing and maintaining family or other personal relationships;
(k) accessing and engaging in work, training, education or volunteering;
(l) making use of necessary facilities or services in the local community including public transport, and recreational facilities or services; and
(m) carrying out any caring responsibilities the adult has for a child.

Paragraph 3: For the purposes of this regulation an adult is to be regarded as being unable to achieve an outcome if the adult:

(a) is unable to achieve it without assistance;
(b) is able to achieve it without assistance but doing so causes the adult significant pain, distress or anxiety;
(c) is able to achieve it without assistance but doing so endangers or is likely to endanger the health or safety of the adult, or of others; or

(d) is able to achieve it without assistance but takes significantly longer than would normally be expected.

Paragraph 4: Where the level of an adult's needs fluctuates, in determining whether the adult's needs meet the eligibility criteria, the local authority must take into account the adult's circumstances over such period as it considers necessary to establish accurately the adult's level of need.

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