Parliamentary and Health Service Ombudsman

Local Government OMBUDSMAN

Complaint ref: 94049 / 11020887 and 11020888

Organisations: Moss Valley Medical Practice

Chesterfield Royal Hospital NHS Foundation Trust

Derbyshire County Primary Care Trust

Derbyshire County Council

Sheffield City Council

Date: February 2014

Introduction

1. This is the final report on a joint investigation by the Health Service Ombudsman and the Local Government Ombudsman into a complaint from Mr TK. The complaint is about the location of care provided to his late brother, Mr RK, during the last few months of his life. TK complains that his and his brother's wishes were not properly taken into account in decisions about where RK should be living and receiving care in 2009. TK says that, as a result, his brother died in care rather than at home, and that this injustice to his brother has caused TK distress.

2. We have investigated several organisations across the health and social services that were involved in making decisions about the location of RK's care. These organisations, and their roles, are:

- Moss Valley Medical Practice (the Practice) was the GPs' surgery with which RK was registered;
- Chesterfield Royal Hospital NHS Foundation Trust (the Trust) managed Calow Hospital, whose staff were involved in decisions about the location of RK's care after he was discharged from hospital;
- Derbyshire County Council's social services department (Derbyshire Council) contributed to some key decisions about the location of RK's care in February and May 2009;

- Sheffield City Council's social services department (Sheffield Council) funded and arranged RK's accommodation and social care until 15 October 2009; and
- NHS Derbyshire County (the PCT) funded and arranged all of RK's health and personal care and accommodation from 15 October 2009. (The PCT were abolished on 31 March 2013.)

Decision and summary

3. We have found that all five organisations involved in RK's care shared responsibility for taking proper account of the law, in particular of the *Deprivation of Liberty Safeguards* that were designed to prevent people without capacity from being deprived of their liberty unfairly. They failed to do so. That was service failure. As a result, RK remained deprived of his liberty in a manner that did not take proper account of the law. This situation caused his brother a great deal of distress. That injustice arose from the service failure we found. We uphold TK's complaint about all five organisations.

Role of the Ombudsmen

General remit of the Ombudsmen

4. Under the *Local Government Act 1974*, the Local Government Ombudsman has wide discretion to investigate complaints of injustice arising from maladministration by local authorities (local councils) and certain other public organisations. She may investigate complaints about most council matters, including providers of social services.

5. The Local Government Ombudsman may carry out an investigation in any manner which, to her, seems appropriate in the circumstances of the case, and in particular may make such enquiries and obtain such information from such persons as she thinks fit.

6. If the Local Government Ombudsman finds that maladministration has resulted in an injustice, she will uphold the complaint. If the resulting injustice is unremedied, she may recommend redress to remedy any injustice she has found.

7. The Health Service Ombudsman is empowered to carry out independent investigations into complaints made by, or on behalf of, people who have suffered injustice or hardship because of poor treatment or service provided by the NHS. Her powers of investigation and approach to upholding complaints and recommending redress are similar to those of the Local Government Ombudsman.

8. Both Ombudsmen look thoroughly at all the circumstances surrounding a complaint and try to resolve it in a way which is fair to all concerned. Where the complaint is justified, we look to the public organisations involved to provide an

appropriate and proportionate remedy for the injustice or hardship suffered by complainants.

Powers to investigate and report jointly

9. The *Regulatory Reform (Collaboration etc. between Ombudsmen) Order 2007* clarified the powers of the Health Service Ombudsman and the Local Government Ombudsman, with the consent of the complainant, to share information, carry out joint investigations and produce joint reports in respect of complaints which fell within the remit of both Ombudsmen.

10. In this case, the Health Service Ombudsman and the Local Government Ombudsman agreed to work together because the injustice claimed by TK – his brother's wish to die at home being frustrated – appeared to have arisen because of decisions made by people working for a number of different organisations. These included people in different roles at a hospital trust, a primary care trust, a GP practice, a care home and two social services departments.

Our decision to investigate this complaint

11. Section 4(5) of the *Health Service Commissioners Act 1993* and section 26(5) of the *Local Government Act 1974* state that the Ombudsmen may not generally investigate a complaint until the complaint has been made to the organisation it is about. However, both Acts allow the Ombudsmen to investigate if they do not think it was reasonable in the circumstances to expect the person to take the complaint to those organisations first. This is a matter for the Ombudsmen's discretion after proper consideration of the facts of the case.

12. In this case, even though TK had not made a complaint to any organisation apart from the PCT, we decided to investigate his complaint about all five organisations. This is because we did not think it was reasonable to expect him to have known which organisations were responsible for making the decisions with which he disagreed. TK reasonably believed that the PCT were responsible for all of the decisions, and complained to them. The Health Service Ombudsman only discovered the extent of other organisations' involvement and responsibilities after carrying out a considerable amount of investigative work. We thought it would be unfair to expect TK to make separate complaints to those organisations at that time, when the Ombudsmen were in the unique position of being able to investigate the complaint about all the organisations as a whole.

How we decided whether to uphold this complaint

13. The Health Service Ombudsman's Principles of Good Administration, Principles of Good Complaint Handling and Principles for Remedy (the Principles) are broad statements of what public organisations should do to deliver good administration, provide good customer service and respond properly when things go wrong.

14. These Principles have been signposted and commended by the Local Government Ombudsman.

15. One of the Principles of Good Administration is particularly relevant to this complaint:

- '*Getting it right*' – which includes public organisations acting in accordance with the law and with regard for the rights of those concerned; following their own policy and procedural guidance; and making reasonable decisions, based on all relevant considerations.

Human rights considerations

16. The Principles incorporate the broader human rights principles that should inform public administration and public service delivery. The FREDA principles are used by government and NHS organisations, among others, as a simple way to ensure that human rights are taken into account in their work. They were chosen to reflect the core values underlying the *European Convention on Human Rights* and the *Human Rights Act 1998*. The FREDA principles are fairness, respect, equality, dignity and autonomy. Of particular relevance to this complaint is autonomy, which includes the right to involvement in decision making and the right to make an informed choice.

The standards

The *Mental Capacity Act 2005*

17. The *Mental Capacity Act 2005* came into force on 1 April 2005. Its purpose is to protect people who cannot make decisions for themselves or lack the mental capacity to do so. The *Mental Capacity Act 2005* defines capacity to make decisions. It sets out, along with related documents, what needs to be done when people do not have capacity.

18. Under the *Mental Capacity Act 2005*, a person lacks capacity to make a decision about something if (among other things) they are unable to understand, use, weigh, or retain information relevant to making a decision. The Act outlines five principles:

- 'A person must be assumed to have capacity unless it is established that he or she lacks capacity.

- 'A person is not to be treated as unable to make a decision unless all practicable steps have been taken to support them to make a decision for themselves.

- 'A person must not be treated as unable to make a decision merely because he or she makes an unwise decision.

- ‘An act done, or decision made, under the Act for or on behalf of a person who lacks capacity must be done, or made, in their best interests.
- ‘Anything done for or on behalf of a person who lacks capacity should be the least restrictive of their rights and freedoms.’

19. If a person is found to lack capacity, their best interests should be assessed. This assessment needs to include:

- considering ‘whether or when the person will have capacity to make the decision’;
- supporting ‘the person’s participation in any acts or decisions made for them’;
- considering ‘the person’s expressed wishes and feelings, beliefs and values’; and
- taking into account ‘the views of others with an interest in the person’s welfare, their carers and those appointed to act on their behalf.’

20. The *Mental Capacity Act 2005* also introduced related services, including the Court of Protection and the Independent Mental Capacity Advocate role.

21. The Court of Protection is the specialist court for all issues relating to people who lack capacity to make specific decisions. The Court can make decisions and appoint deputies to make decisions about someone’s healthcare and personal welfare.

22. People making decisions about serious medical treatment or a change of accommodation for an adult who lacks capacity must consult with someone, such as a family member or close friend of the adult. If the person making the decision considers that there is no one who is willing and able to be consulted about the decision, an Independent Mental Capacity Advocate must be appointed. The role of the Independent Mental Capacity Advocates is to ensure that the person making the decision has properly considered how the decision will affect the person who lacks capacity. The Advocate’s role is not to make the decision or to offer their own opinion on the person’s best interests, only to make sure the decision-making process is carried out properly.

23. The *Mental Capacity Act 2005 Code of Practice* explains that:

'If someone wants to challenge a decision-maker's conclusions, there are several options:

- *Involve an advocate to act on behalf of the person who lacks capacity to make the decision …*
- *Get a second opinion.*
- *Hold a formal or informal 'best interests' case conference.*
- *Attempt some form of mediation …*
- *Pursue a complaint through the organisation's formal procedures.*

'Ultimately, if all other attempts to resolve the dispute have failed, the court might need to decide what is in the person's best interests.'

***Deprivation of Liberty* safeguards**

24. The *Deprivation of Liberty Safeguards Code of Practice* (the safeguards) supplements the *Mental Capacity Act 2005*'s own code of practice. The safeguards came into force on 1 April 2009. They apply where someone lacks capacity to consent to care or treatment thought to be in their best interests which might involve depriving them of their liberty. The point of the safeguards is to prevent people being deprived of their liberty improperly or unlawfully.

25. The safeguards were developed following a judgment by the European Court of Human Rights (the European Court) known generally as the Bournewood judgment. That case was about 'HL', a man who lacked capacity and could not speak, who was taken from his home and detained in Bournewood hospital on an informal basis in his best interests. He could not consent to this. HL's carers, who were prevented from visiting him in case he wanted to leave with them, disagreed with the decision. After exhausting the English courts, they appealed to the European Court. The European Court found that HL had been deprived of his liberty, and that it was a breach of the *European Convention on Human Rights*, because the deprivation was not in accordance with a procedure set out in the law and there was no way for HL to apply quickly to a court to establish its lawfulness.

26. The safeguards were developed in response to this judgment, in order *'to provide a proper legal process and suitable protection in those circumstances where deprivation of liberty appears to be unavoidable, in a person's own best interests'*.

27. The safeguards state that someone can only be deprived of their liberty if:

- *'It is in their own best interests to protect them from harm;*

- *'It is a proportionate response to the likelihood and seriousness of the harm;* and

- *'There is no less restrictive alternative.'*

28. The safeguards' *Code of Practice* states that certain factors can be relevant in identifying whether the steps being taken on behalf of the person who lacks capacity amount to deprivation of their liberty. The decision maker should always consider:

- The views of the relevant person, their family or carers; and

- Whether there are any less restrictive options for delivering care that avoid deprivation of liberty altogether.

29. The formal safeguarding process involves a *'managing authority'* (usually a hospital or care home) seeking authorisation from a *'supervisory body'* (this is usually an NHS primary care commissioner or local authority, depending on whether the care is commissioned by the NHS or by social services). They do this by applying in writing, using a standard form, for *'standard authorisation'* to take the action that involves depriving the individual of their liberty. This form must include certain information, if available, including a view on whether an Independent Mental Capacity Advocate should be instructed. There is no requirement for an Independent Mental Capacity Advocate to be instructed where, as in RK's case, they have a representative – but one may still be appointed if that person is not a *'paid "professional" representative'* or if the supervisory body *'believes that instructing an* [Independent Mental Capacity Advocate] *will help to ensure that the person's rights are protected'*.

30. If the managing authority and the supervisory body are the same organisation, the person who assessed the individual's best interests cannot be an employee of that organisation.

31. The managing authority can, *'where deprivation of liberty unavoidably needs to commence before a standard authorisation can be obtained'*, issue *'an urgent authorisation which will make the deprivation of liberty lawful for a short period of time'*. An urgent authorisation can only be issued after or at the same time as an application for standard authorisation. It can provide authorisation for a maximum of seven days.

The investigation

32. We have looked at all the relevant evidence for this case, including RK's medical notes from the Practice and the hospital, his social services records from Derbyshire Council and Sheffield Council, and his care home records, as well as the papers showing how the PCT handled TK's complaint. We have spoken to TK's

advocate and have taken account of TK's comments as well as those from all five organisations that we have investigated.

33. We also took advice from two of our clinical advisers: a GP (the GP Adviser) and a registered mental health nurse (the Mental Health Nursing Adviser). Our clinical advisers are experts in their respective fields. In their role as advisers they are completely independent of the NHS.

34. We have not included in this report everything we looked at during the investigation. But we have included everything important to the complaint and to our findings.

35. We have shared a draft of this report with TK and with all five organisations. We have taken all of the comments they submitted into account.

What happened

36. Mr RK was born in September 1932. He and his brother Mr TK had lived together all their lives. They had also worked together in a colliery before retiring. They believed strongly in looking after their own.

37. From around 2006, RK was unable to walk. He had developed Alzheimer's disease. RK continued living at the family home with his brother and a cousin. TK was his brother's primary carer.

38. Toward the end of 2008, RK was suffering from increasing difficulty breathing. On 12 December RK's GP visited him at home about this. The GP wrote that the house was *'in a terrible state'*, describing the air as *'acrid'* (bitter and irritating). The GP thought that RK's breathing difficulty could be related to the poor air conditions.

39. After a discussion at one of their regular care of the elderly meetings, the Practice asked one of their district nurses to visit RK. She did so on 19 December. She described the conditions as being *'extremely poor, squalid'*. She had concerns about the lack of cooking facilities and wondered if RK was eating well enough.

40. Feeling that they had a *'duty of care'*, the Practice planned to discuss a referral to social services at their next care of the elderly meeting. In the meantime, RK was found to be diabetic.[1] Because RK needed to start having regular injections of insulin, and in order to *'address the housing and social conditions'*, the Practice decided that he should be admitted to a step-up bed (a temporary placement in a nursing home as a substitute for hospital admission). On 22 January 2009 he was admitted to a step-up bed in Eckington Court nursing home.

[1] Diabetes is a condition in which the body does not have enough insulin (a hormone that regulates blood sugar levels). Treatment can include daily injections of insulin.

41. A Derbyshire social worker visited RK on 3 February. (Although the brothers lived in Sheffield, the Practice with which RK was registered is in Derbyshire. This is why both social services departments were involved.) RK did not remember why he was in the nursing home but said he wanted to go home. Around this time, Derbyshire Council were arranging to assess RK's home to see what equipment and support would be required when he was able to return.

42. In February, Sheffield and Derbyshire Councils were in contact with each other, discussing who should be paying for RK's care. Staff at the nursing home asked the Practice about discharge arrangements after, they said, not getting an answer from Sheffield Council.

43. A form filled in on 23 February by Sheffield Council requesting a special cushion for RK's wheelchair noted that RK was awaiting discharge home *'ASAP pending equipment delivery'*.

44. On 3 March Sheffield Council told the Practice that they were *'hoping to sort out* [a] *care package in a matter of days'*.

45. The following day RK was admitted to Calow Hospital (managed by the Trust) with breathing difficulties. The evidence shows ongoing discussions between social workers, doctors and other professionals about RK's returning home after being discharged.

46. In early April, the hospital notes say, RK was asking to go home. Derbyshire Council's hospital social work team requested a mental capacity assessment on 6 April. They continued to liaise with Sheffield Council about RK's care arrangements.

47. Over the next two weeks, the doctors in charge of RK's care asked a consultant nurse in mental health for help assessing his capacity. The capacity assessment was postponed until RK was properly hydrated (that is, until he had been regularly drinking enough water). Further information was gathered from TK in the meantime, including that RK had previously been forgetful but was now unable to hold a conversation.

48. A note of a doctor's ward round on 20 April says the doctor *'feels* [RK] *does not have capacity to understand* [discharge] *plans – but expressed wish to return home, feeling shared by his brother'*. The doctor requested a second opinion from the consultant nurse in mental health.

49. On 23 April there was a multidisciplinary team meeting. The team felt *'that* [RK's] *needs would be best met in a nursing home environment'*, but noted that TK wanted his brother home with support from carers and a district nurse (to administer insulin). Because there was no recent, formal capacity assessment, the team decided that one should be carried out.

50. On 29 April a doctor noted that RK was *'unable to tell me his understanding of* [the] *current situation'*. On 1 May staff from Derbyshire Council, the Practice and the hospital jointly completed an NHS continuing care assessment.[2] The decision was that RK should be considered for full funding as he had high and unpredictable health needs. In particular, he was said to lack capacity, needing his brother to act in his best interests.

51. Another assessment of RK's home was done on 12 May, by a district nurse employed by the Practice. She was concerned that the environment was not suitable for RK. Floors were covered in '*slippy soot*' and there were no viable cooking facilities. The district nurse contacted Sheffield Council's environmental health department with her concerns, and told the PCT she thought that visiting staff would be at risk from the smoke.

52. On 14 May, at a Practice care of the elderly meeting, the Practice decided that RK *'cannot go home under these conditions'*. Three days later a Derbyshire social worker discussed the situation with hospital staff and her manager, deciding that *'in light of the delays and confusion over information received it would be in* [RK's] *best interests at this point to be placed in April Park* [care home]*'*. (Sheffield Council explained to us, during our investigation, that April Park was nearer the brothers' home and therefore it was easier for TK to visit.)

53. RK was admitted to April Park on 22 May. At this point the plan was for April Park to provide short-term care while the family home was made *'safe and suitable for nurses/carers to visit'*.

54. On the day RK was admitted, a deprivation of liberty assessment was carried out at April Park. The form says *'If the answer to some or all of the questions below is yes then consideration must be given to applying for authorisation for deprivation of liberty'*. There are eight questions on the form, all of which have been answered *'no'*. The fourth question is *'Have relatives or carers asked for the client to be discharged to their care, and been refused?'*. The form does not give the name of the person who completed it, but Derbyshire Council told us that it would have been a best interests assessor from Sheffield Council.

55. In early June, the Practice showed TK how to administer insulin to his brother. TK was *'coping well'*. On 9 June a care manager – a social worker – from Sheffield Council (the care manager) visited the family home, noting that it was still dirty, and another visit was arranged for two weeks' time. The aim was to arrange RK's return home when the house was cleaned. The care manager offered help with cleaning the house but TK said he did not want any help.

56. On 19 June the care manager asked one of the Practice's district nurses if the GPs could assess RK's capacity to make a decision about his care. A week later the Practice's district nurse and the care manager visited RK's home. Although they saw

[2] The NHS is responsible for funding all aspects of care, including accommodation and personal care, for patients with a primary health need. PCTs were responsible at the time for paying for that care.

that TK had cleared a lot of debris, they remained concerned about the amount of soot in the house. They decided an environmental risk assessment and further equipment would be needed before RK could return home.

57. On 7 July one of the GPs carried out a capacity assessment for RK. The assessment said:

> ‘*Appears frail – appetite not very good.*
>
> ‘*Poor short term memory.*
>
> ‘*Difficulty grasping essential points of discussion ie about being discharged home. Poorly oriented in time and place – able to recall date of birth but not current year – able to identity self, brother, but believes his father still alive. Unaware of present surrounding.*
>
> ‘*Cannot appreciate that he is frail and will therefore need support at home. Unable to recall elements of the conversation 5 mins later. Therefore regarding issue of being discharged to his own home doesn’t demonstrate understanding of the concept of returning home, impact of his poor health on being able to manage* [activities of daily living] *at home and unable to weigh the pros/cons of this issue because has poor memory (not able to address the matter coherently).*
>
> ‘*Poor recall of entire discussion.*
>
> ‘*Therefore I do not feel he has capacity to make the decision about being discharged back to his own home.*’

58. Sheffield Council’s care manager visited TK twice during July. She thought that RK should return home to be cared for by his brother with a care package to help. The plan was for RK to go home for a trial period towards the end of July.

59. A Sheffield Council review form dated 24 July says:

> ‘[TK] *is demanding that his brother* [RK] *returns home, he has always wanted to care for his brother and promised he would never allow him to be transferred or live in a residential home.*
>
> ‘ …
>
> ‘*During* [RK’s] *hospital stay, he was deemed as lacking in capacity to make an informed decision regarding his request to return home. A mental capacity assessment was completed in* [hospital] … *but we* [believe] *there is no evidence based information to support that claim.*’

60. By 3 August some day care had been arranged but RK was on the waiting list for night time care visits. However, by this time his health had deteriorated: he had

developed a pressure sore[3] and was not eating well or talking much. The nurses caring for RK thought his health would suffer more if he went home. By 6 August the PCT and Sheffield social services apparently agreed that they were now *'treating this person as permanent, not respite'*.

61. On 2 September there was a care review at April Park, attended by two Sheffield Council social workers, a PCT nurse assessor, the nursing home's deputy manager and TK. They recorded that:

> '[RK's] *brother* – [TK] – *would like for* [RK] *to return home however it was agreed that due to his needs* [RK] *would be best placed in the nursing home … to discuss this with* [RK] *and explain the reasoning for this decision as it is felt by the* [multidisciplinary team] *that his physical condition could deteriorate at home.*
>
> *'…if* [RK] *very unhappy* [with] *recommendation we will consider discharge home with social services package. Agreed to return in 6-8 weeks to do full review … to see if* [RK] *has accepted this decision and is settled in the home.'*

62. In early September the PCT decided that RK was not eligible for full NHS funding. By 11 September RK's condition had deteriorated and on that day he was admitted to hospital. He was placed on the end of life care pathway.[4] However, on 14 September RK's condition was much better. He was taken off the end of life care pathway and discharged back to April Park the following day.

63. In late September an advocate from the Sheffield Centre for Independent Living (the advocate) began working with the brothers. The PCT started to gather information to inform a further review of RK's eligibility for full NHS continuing care funding. A meeting was held at the nursing home on 15 October. The PCT's nurse assessed RK as eligible for full NHS funding. The nurse assessor said she thought RK needed caring for in a nursing home, but Sheffield Council recommended that RK be cared for at home. The nurse assessor's recommendation was considered and agreed by a PCT funding panel on 21 October. At this point the primary responsibility for RK's care transferred from Sheffield Council to the PCT.

64. On 30 October the advocate wrote to the PCT explaining that RK wished to return home, and asking how the care package would be co-ordinated.

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[3] A pressure sore (or bedsore) is a skin wound arising from prolonged periods of sitting or lying down. They can be very painful, and may become infected. They are regarded as a serious medical condition.

[4] When doctors believe that someone is dying, an end of life care pathway can be used to guide their treatment. Typically treatment will concentrate on keeping the person comfortable in the short term rather than treating any long term conditions.

65. On 2 November Sheffield Council's care manager wrote that the PCT had:

> *'recommended that* [RK] *requires 24 hour nursing care within a care home setting with qualified nursing staff, he has not got the capacity to make his own decisions, they therefore would not be pursuing him returning home. I have emailed* [the advocate] *… and as recommended by my team manager I have cancelled his care package.'*

66. On 13 November the advocate wrote again to the PCT explaining that RK and his brother wanted him to return home, and that RK had decided this in advance of losing capacity. He asked them to respond within five working days to explain *'What urgent steps will be taken to arrange a package of care for* [RK] *to return home'*. The advocate said that if the PCT did not accept either that RK had capacity to make the decision or that he had made the decision in advance, then they should arrange a best interests meeting within ten days. If that did not happen, the advocate said, he would consider applying to the Court of Protection for a ruling.

67. On 17 November 2009 Sheffield Council's care manager wrote to the PCT's continuing care case manager. She urged the PCT to reverse their decision not to allow RK to return home. She wrote that:

> *'When I have visited* [RK] *to discuss staying in April Park his reaction has always been the same. He starts to become distressed and on the last 2 occasions has started aspirating.*[5] *He does not settle until the subject is changed. I strongly believe this indicates that he has some awareness of his whereabouts and would benefit from being more settled in his own home environment …*
>
> *'it has always been acknowledged via* [multidisciplinary team meetings] *and ward assessments that despite* [RK's] *lack of capacity to make decisions it was in his best interests to return home with his brother and a substantial package of care. It was agreed that he be transferred into April Park Nursing Home for a short time until his brother completed some improvements to his home circumstances.'*

68. The care manager wrote that despite the complexity and risk involved in RK returning home, his brother had *'proven to me that he is capable'* of caring for RK with the support of carers, Age Concern and district nurses.

69. On 18 November TK wrote to the PCT's continuing care case manager. He said:

> *'the doctor has told me* [RK] *could die at anytime and anywhere, I told him well that's it then he may as well come home and die here instead of at any hospital or care home. This is what* [RK] *wants too … My feelings are that I've done it all before and I can do it again … I can do it all again because he is my*

[5] Aspirating is inhaling material such as food or spittle into the windpipe and lungs.

brother … I think that it is just not on … I want mine and my brother's wishes to be taken into the picture, to see what we want and feel.'

70. On the basis of the care manager's letter, on 19 November the PCT decided to hold a multidisciplinary team meeting to discuss the viability of RK going home safely. On 25 November they wrote to TK to tell him this. They added that they would be in touch shortly with further details. TK was told that a further assessment of his brother would be carried out on 18 December.

71. In the early hours of 10 December RK was found collapsed at April Park by care workers. He was taken to hospital where, a few hours later, he died.

The complaint to the PCT

72. In January 2010 an advocate at Age Concern wrote to the Trust (who passed the letter to the PCT). She said that *'regardless of the end of life issues'* the PCT failed to take account of RK's advance and ongoing wishes. She wrote that '*they also failed to act within the spirit and letter of the Mental Capacity Act'*. Enclosed with this was a letter from TK. Referring to the meeting on 15 October (paragraph 63) he asked: *'why was it that his wishes of returning home were overridden by the virtue of a change in his funding package?'*

73. TK explained the impact this had had on him:

> *'Part of my life has now been taken away, this hits me so much more at night when my brain is going at 90mph and I'm left wondering what else I could have done to get my brother home. I complied with all agencies involved, and never stopped the fight to try and get my brother home.'*

74. On 1 March 2010 the PCT replied. They said that the earliest date everyone could have got together for a review of RK's care was 18 December 2009. They said that home care for RK would have been complicated, *'but if it could have been provided safely and effectively we would have been willing to commission it'*.

Comments from the organisations we are investigating

75. Most of the organisations we are investigating did not have an earlier opportunity to respond to the complaint (paragraph 12). We asked all of the organisations to comment when we began the investigation. Their views on the complaint are summarised in the following sections.

The PCT's comments

76. The PCT told us that they:

> *'were definitely looking to commission what would have been a very complicated package but unfortunately* [RK] *died before anything was put in*

place. The Continuing Care Team records … demonstrate the action planned and taken to arrange the home care package for this patient.'

Sheffield Council's comments

77. Sheffield Council told us that RK was their client throughout the period we are investigating. They said they were fully supportive of RK's wish to return home and planned for him to do so, and that their assessments consistently demonstrated this. Sheffield Council said they did not prevent this from happening but worked with TK to ensure the home was safe for his brother's return.

78. Sheffield Council said that the condition of the home was only one factor. The other was RK's deteriorating health. By 24 July the Council was satisfied the home was fit for RK's return – but by then he had developed pressure sores (paragraph 60) which in turn reduced the likelihood of his return home.

79. Sheffield Council said their care manager at the time was told by the district nurse that RK's lack of capacity had already been established. They understood, therefore, that no further capacity assessment was required. They also said they were led to believe that a best interests meeting had taken place in hospital in April 2009. However, they had no documentary evidence that these events had occurred.

80. Sheffield Council said they accepted that a best interests meeting should have taken place in June or July 2009. They said that RK was not offered an Independent Mental Capacity Advocate because his brother was representing him. They said they had offered TK an advocate to help him apply for NHS continuing care funding for his brother.

81. Sheffield Council said the placement at April Park was renewed every four weeks, showing that it was always meant to be short-term. They said the records of their discussions with TK about cleaning the house, and their offers to help him with that on 9 and 26 June and on 8 and 24 July 2009 (paragraphs 55, 56 and 58), show that they had aimed to get RK home.

82. Sheffield Council said they very much regret that RK did not return home. They said that their care manager made it clear to the PCT that she thought he should return home, when RK became the responsibility of the PCT (paragraph 67).

Derbyshire Council's comments

83. Derbyshire Council said that they first became aware of RK when he moved to Eckington Court. They explained why they became involved in RK's case even though he lived in Sheffield Council's area. It was because he was an inpatient at Chesterfield Royal Hospital and so Derbyshire Council's on-site social work team assisted Sheffield Council with arranging RK's discharge from hospital.

84. Derbyshire Council said that both brothers were clear that they wanted RK to return home. Derbyshire Council said they supported the brothers' view. They say that the records show they worked in conjunction with Sheffield Council to make this happen. They pointed out that they identified a package of care to enable him to return home. They said that at no time did they facilitate RK's admission into long-term care.

85. Derbyshire Council said that they first requested a mental capacity assessment on 6 April 2009 (paragraph 46). They do not have a copy of any such assessment. However, they noted that the assessment carried out on 1 May showed that RK had been assessed as lacking capacity to make decisions about the location of his care (paragraph 50).

86. Although no decisions were made about RK's long-term care arrangements while they were involved in his case, Derbyshire Council told us, the 1 May assessment showed that those involved intended that he would return home with a care package.

87. Derbyshire Council confirmed that a best interests meeting was not held during their involvement in RK's case. However, they argued that RK's interests and, in particular, his stated wish to return home, were consistently considered by the professionals involved. They said this was shown by, for example, the fact that they had ordered equipment for RK at home (paragraph 43). They added that respite care was arranged as a stepping stone to RK's return home.

88. Derbyshire Council said that an Independent Mental Capacity Advocate was not required during its involvement in the case. They said there was no fundamental disagreement on the course of action required: that RK should return home. They said that if this was not happening, they would have called a best interests meeting and applied the safeguards. They said they sought to ensure that RK returned home and at no time did they deprive him of his liberty.

89. Derbyshire Council said that their involvement in RK's case ended on 22 May when he moved to April Park (paragraph 53).

The Trust's comments

90. The Trust said they had reviewed their records of RK's time in hospital. They said that when RK was admitted to Calow Hospital in March 2009, staff discussed RK's mental capacity and *'his ability to contribute to decision making'*. The Trust said their staff raised their concerns about TK's ability to cope if his brother returned home with him. They said that TK attended multidisciplinary team meetings at which these concerns were discussed, and that he was then given time to decide whether he would still like his brother to return home.

91. They said that it was clear that *'there was a process in place to determine where a safe place of care would be following discharge'*. They stressed that it was

TK's decision that his brother should be transferred to the step-down facility. They said TK had not said at the time that he was unhappy with the process. If he had, the Trust said, they *'would willingly have met with him to discuss his brother's care and discharge plan and to address his worries'*.

The Practice's comments

92. The Practice told us that their district nursing team's assessment, carried out in conjunction with social services, was that RK *'would not be fit at home'*. After he was discharged to April Park, the plan was still for him to return home, but increasingly he struggled with problems with his diet. The Practice said that RK's GP records show that there was ongoing assessment of his home situation.

93. They say that *'despite'* the conclusion that RK did not have capacity (paragraph 57), the Practice *'continued to try and plan to get RK home safely'*. However, they said, he became increasingly frail and lost weight, even after receiving help from a dietician following his admission to hospital in September 2009.

Clinical advice

Mental health nursing advice

94. The Mental Health Nursing Adviser noted that when RK was in Calow Hospital between March and May 2009, he and his brother had repeatedly stated that RK's wish was to return home when he was well enough to leave hospital. Since the health professionals believed returning home was not in his best interests, these repeated statements should have indicated to them that a deprivation of liberty order was required. The options would have been discharging RK home in accordance with his wishes, with a care package in place, or applying to the supervisory body to deprive him of his liberty in his best interests by transferring him to a care home.

GP advice

95. The GP Adviser said that the GPs had a responsibility under the *Mental Capacity Act 2005* (paragraph 17). The GP Adviser said that in similar situations, where care packages at home are being arranged, the GP's role is usually to provide clinical treatment and an overview of the needs of the patient. GPs are responsible for the 'holistic' care of their patients (addressing all aspects of people's needs: psychological, physical and social).

96. In RK's case, it had been agreed that going home was in his best interests but also that a complex care package was needed. Multidisciplinary meetings were held (usually led by GPs), but there do not seem to have been any discussions about appointing an independent advocate or arranging a best interests meeting.

97. The GP Adviser added that the GPs did not have sole responsibility for arranging an advocate. The GP Adviser said she was surprised, given the number of meetings and discussions held by the continuing care team, that this issue was apparently not raised by any of the healthcare professionals. She said the GPs should have been aware of the need for an independent mental capacity advocate, even though RK had his brother to support him. The GP Adviser said that RK needed the support of an advocate who was knowledgeable about the rights to which he was entitled. Having an independent advocate earlier would have helped him make his views known more strongly.

98. The GP Adviser said that the GPs involved in the care of RK carried out regular reviews whilst he was in the step-down bed and noted that RK's care was also discussed by a multidisciplinary care of the elderly team meeting. The purpose of such meetings is to make decisions regarding the recommended treatment of individual patients. The GP Adviser said that this should have enabled team agreement on the best course of action with involvement of senior, experienced professionals to ensure all aspects of RK's needs were addressed.

99. The GP Adviser said that as the health care professionals felt RK was not suitable for discharge to his own home, and that this clashed with his own and his brother's wishes, the clearly stated steps in the *Mental Capacity Act 2005* should have been followed: namely, involvement of an Independent Mental Health Advocate or arrangement of a best interests meeting. If the GPs had any concerns about a potential conflict between professional advice and RK's and his brother's wishes, they should have arranged an Independent Mental Health Advocate to support them. There were also no discussions with RK's brother about prognosis or end of life decisions to enable advanced care planning, or any discussions around simply allowing him to go home to die.

Our findings

100. RK wanted to be at home. He did not want to die in a hospital or a care home. RK's brother also wanted him to return home and he told hospital, council and PCT staff this from the start. Both councils acknowledge this and say they agreed that RK should have returned home (paragraphs 77 and 84).

101. The professionals who worked with RK had genuine concerns that his health would suffer if he returned to the family home. Its condition was poor and some professionals thought the property posed a risk to RK and even to professionals who might visit him there (paragraph 51). During the course of their involvement, RK's health deteriorated and it would have been more difficult to put together a care package for him at home. Given all this, we can understand why the professionals who were involved in making decisions about his care were not convinced that going home was the best thing for RK.

102. However, whether or not RK went home was not their decision to make. RK was an adult who arguably lacked capacity to make his own decisions about the location

of his care. As such, he was in precisely the position for which the safeguards were developed (paragraph 26). The professionals involved should have taken proper account of the *Mental Capacity Act 2005* and the safeguards.

103. As early as 3 February 2009 (paragraph 41), RK told staff he wanted to go home. By 18 February his brother had told the professionals that he shared this wish. Even if they thought this decision unwise, the doctors, nurses and social workers should have respected it and allowed or arranged for RK's return – unless they thought RK lacked capacity to make that decision. And, under the *Mental Capacity Act 2005*, they should have assumed that RK had capacity, unless it was established that he did not (paragraph 18).

104. It was therefore very important to properly assess whether or not RK had capacity to make a decision about the location of his future care.

105. Staff at the hospital correctly tried to establish whether RK had capacity to make the decision about where he should live. Their decision to seek expert help from a consultant nurse in mental health indicates that hospital staff appreciated the need for a robust capacity assessment. There is also evidence to show that staff wanted RK's capacity to be assessed when he was in a better clinical condition – in mid-April they postponed assessment until his dehydration had been treated (paragraph 47). That was in line with the *Mental Capacity Act 2005* directions to take practicable steps to support RK in making the decision for himself (paragraph 18).

106. However, while staff apparently *'felt'* that RK lacked capacity (paragraph 48), no formal capacity assessment was carried out before he was discharged. We can understand why the hospital thought the best way forward was to discharge RK to a step-down bed temporarily while his brother prepared the family home for his return. However, the *Mental Capacity Act 2005* gives clear and compulsory instructions. The hospital did not establish that he did not have capacity. Yet their decisions on his behalf contradicted his stated wish to go home. The medical and social services staff did not take proper account of the law, or of RK's right to autonomy. They did not 'get it right'.

107. From 22 May (when he was discharged from hospital) the responsibility for RK's medical care transferred to the Practice. The responsibility for his social care transferred to Sheffield Council. District nurses working out of the Practice, and nurses in the nursing home, were also involved in his care. The GPs, the nurses and the social workers involved in arranging and providing RK's care shared the responsibility for ensuring that he was not being wrongly deprived of his liberty.

108. On the day that RK was admitted to April Park, a deprivation of liberty assessment was completed (paragraph 54). This assessment was incorrect. RK's brother had asked for him to be discharged home and been refused, so the answer to the fourth question should have been 'yes'. It may be that the person who completed the form did not know about TK's request for his brother to be discharged

to his care. But this form was the only evidence on file of an explicit consideration of whether RK was being deprived of his liberty, and the assessment was wrong.

109. During RK's first month in April Park, Sheffield Council's social workers and PCT staff were in touch about RK's ongoing care. Evidently the social workers and PCT staff were acting in what they believed to be RK's best interests. They had justifiable concerns about his returning home. However, it was not their decision to make. Even if deciding to return home was foolhardy, if RK had capacity to make that decision, the health and social care professionals were not allowed to stand in his way. But no one in the PCT or the Practice seems to have realised that the safeguarding process should be followed and that, until it was, RK remained deprived of his liberty because of his circumstances – ones that the safeguards were constructed to prevent.

110. The first step required was to assess RK's capacity. On 19 June, almost a month after RK was admitted to April Park, one of Sheffield Council's social workers noted that a mental capacity assessment ought to be carried out (paragraph 56). The assessment took place on 7 July (paragraph 57), by which time he had been in April Park for over six weeks. This assessment established that RK did not have the capacity to understand what was involved in returning home.

111. The next step under the *Mental Capacity Act 2005* should have been to formally assess RK's best interests (paragraph 19). This should have included considering whether he would be likely to regain capacity, helping him participate in decisions made about the location of his care, considering his repeatedly expressed wish to return home, and taking into account his brother's wishes and the value the family placed on caring for their own (paragraph 36). None of this was done.

112. If a formal assessment of RK's best interests had concluded that it was in his best interests to be cared for in a nursing home, then the safeguards would have been engaged and the *Code of Practice* should have been followed (paragraph 29). That would have meant taking into account the brothers' views, the alternatives to depriving RK of his liberty, and whether depriving him of his liberty was proportionate in the circumstances. It would also have meant considering whether an Independent Mental Capacity Advocate should be appointed. And it would have meant formally applying to Sheffield Council for authorisation to deprive RK of his liberty. (If an employee of Sheffield Council had made this application, they would first have had to ensure that a best interests assessment had been carried out by someone who was not employed by Sheffield Council.)

113. Any deferral of the decision whether to discharge RK, after his lack of capacity had been established, was also in effect a decision to continue depriving him of his liberty – without any proper justification for doing so.

114. From 21 October, responsibility for RK's care transferred to the PCT (paragraph 63). At this time, Sheffield Council was still preparing for RK's return home, but the PCT apparently disagreed with that course of action (paragraph 65). It

is easy to see why TK believed that his brother's wishes were overridden because of a change in who was funding his care (paragraph 72). In fact, he and his brother's wishes had been continually overridden for over six months by that point. And it was not the PCT's place to simply decide, without following the safeguarding process, that RK would not go home.

115. The PCT had the primary responsibility for arranging RK's care during the last few weeks of his life. Of course, they did not know these would be the last few weeks of his life – although there were indications that his life was coming to an end. Certainly, when they received TK's letter of 18 November (paragraph 69) they should have been aware that RK *'could die at any time'* and that he and his brother wanted him to go home. They received two other letters, from the advocate and Sheffield Council's care manager, both urging them to reconsider their decision not to allow RK home. The advocate's letter alluded to the process required by the *Mental Capacity Act 2005*, and to the urgency of the situation (paragraph 66). This, and the fact that the PCT had recently overturned a long-established plan to return RK to his home, should have prompted an urgent reaction from the PCT. They should have aimed to sort matters out within hours, or days at most. Instead, they arranged to have a meeting a month later. Sadly, this was too late and, before the meeting could take place, RK died.

116. The comments submitted by the NHS organisations and councils during the investigation reveal two things in particular. Firstly, that everyone involved in RK's care was acting in good faith, with what they believed were RK's best interests at heart. Indeed, the records show that many individuals put a lot of effort into RK's case. And second, the comments reveal that nobody realised the consequences of what they were doing – or not doing. The organisations explained why they thought RK's home was unsuitable for his return, how they were working to fix that, their ongoing support for RK's desire to return home, and their regret that this did not prove possible in the end. All of this is laudable. But throughout much of 2009, RK was deprived of his liberty, against his wishes. Even in their submissions to us during the investigation, none of the organisations identified this.

117. Although we have criticised the organisations involved in arranging RK's care for failing to take account of the safeguards, we recognise that these events took place around and shortly after the safeguards were introduced – and that new laws and processes take time to become part of everyday working life. However, the safeguards were in fact in force, and they were the culmination of events and debates that had been taking place over the previous few years in those professional fields (paragraph 25). They did not arrive out of the blue. We also note that even when the organisations reflected on what happened three years later, in order to submit their comments during our investigation, they still did not identify the problem.

118. Professionals from all five organisations worked hard together with the best of intentions. But their failure to take proper account of the law meant that the service

they provided to RK in that respect fell significantly below the standards. They did not 'get it right'. That was service failure.

Injustice

119. If the safeguarding process had been properly followed, RK's best interests would have been properly and formally assessed. Whether his brother or someone else was appointed as RK's personal representative, RK's views would have been aired and properly considered. A reasonable decision, based on all relevant considerations, could have been taken (paragraph 15).

120. A proper best interests decision might have meant that RK would have been discharged home as soon as he was medically stable enough. Even if that decision had in some respects led to his being less comfortable – possibly even shortened his life – it would have been what he wanted: to continue living, and then to die, in his own home. He would have retained his autonomy. That would also have saved TK the distress he has suffered as a result of not being able to ensure his brother's wishes were respected.

121. The safeguarding process, properly followed, might have led the responsible organisations to conclude that it was in RK's best interests to have care delivered in a hospital or care home and that there was no less restrictive option available. If that had happened, TK might still have been left distressed by the fact that his brother's wishes had not been respected. But he would at least have known that those wishes had been taken into account and that there was nothing more he could have done in his attempt to have them granted. He would not have been *'left wondering what else* [he] *could have done'* to get his brother home (paragraph 73). That might well have reduced the distress that he suffered as a result of what happened.

122. The injustice that RK suffered as a result of the organisations' service failure was losing the opportunity to go home to die as he wanted. He was deprived of his liberty for the last ten months of his life, in a way that did not take proper account of the law. His autonomy was compromised (paragraph 16).

123. The injustice that TK suffered was the distress at being unreasonably thwarted in his attempts to have RK's, and his own, wishes respected.

124. Having found injustice in consequence of service failure, we uphold TK's complaint.

Responses to the draft report

125. We shared a draft of this report with the Practice, the Trust and both councils, as well as with TK. All of them have now accepted the findings and recommendations. We also shared the report with the Department of Health, who

responded on behalf of the former PCT. The responses from the other four organisations are summarised below.

The Practice

126. The Practice stressed that, at the time of these events, the safeguarding procedures were new and their *'level of awareness of them was low'*. It has since increased. The Practice told us that they have improved their links with social services and local care homes since these events. In particular, social workers attend their weekly multidisciplinary team meetings, which has improved communication and improved the Practice's awareness of social care services. Their service to nursing homes has been improved by having the same doctors visiting regularly. They have quarterly meetings with local nursing home managers. Clinicians at the Practice have also undertaken training about the safeguards and Independent Mental Capacity Advocates.

Sheffield Council

127. Sheffield Council told us that they regretted and were sorry for their part in RK's being denied the opportunity to return home, and the effect this had on TK. They said their *'service has moved on significantly since 2009 in the practical application of* [the safeguards]*'*, but that they accepted *'without hesitation'* the need to review current practices. This review was being prioritised.

Derbyshire Council

128. Derbyshire Council told us that their staff sought, and acted upon, RK's and his brother's views throughout their involvement in his care. Staff were working toward RK's leaving hospital. Derbyshire Council pointed out that they were neither the managing authority nor the supervisory body for RK at any point.

129. Derbyshire Council said that they had since *'developed a system which is able to cope with one of the busiest* [safeguarding] *referral points in the country'*. Among other things, they have developed expertise and deliver training and awareness sessions to families and carers and professionals from care homes, the police and the NHS across Derbyshire. They said that their safeguarding work resulted in Derbyshire Council's team *'being runners up in the Social Worker of the Year Best Awards 2012 (Best Team category)'*.

The Trust

130. The Trust acknowledged *'with regret'* the shortfalls in the decisions made at their hospital that are highlighted in this report.

Remedy

131. In this section we make three recommendations to the organisations we investigated. We are pleased that all the organisations have agreed to carry out the action that we recommend. (The Department of Health has agreed to implement our recommendation to the former PCT on their behalf.)

132. In order to put things right for TK, we recommend that the Practice, the Trust and both councils should write to him to acknowledge and apologise for their part in the failings identified in this report, and for the injustice to RK and TK. This should be sent within one month of the date of this final report.

133. We also recommend that all five organisations pay £200 to TK in recognition of the injustice we have found: a total of £1,000.[6]

134. Finally, we remain concerned that the organisations did not, more than three years later, identify what went wrong in this case. That suggests that there may be an ongoing lack of understanding of the *Mental Capacity Act 2005* and the safeguards. We recommend that the Practice, the Trust and both councils review their practices to establish whether the safeguards are embedded and routinely applied by staff in these circumstances. They should share the results of this review with us and with TK.

135. If any of these reviews suggest that this is not the case, then the organisation concerned should prepare an action plan that describes what they have done and/or plan to do to ensure that the organisation, and the individuals involved, have learnt the lessons from the failings identified by this upheld complaint; and describes what they have done, and/or plan to do, including timescales, to avoid a recurrence of these failings in the future. They should share these action plans with us and with TK. The NHS organisations should also share any action plan with the Care Quality Commission (the regulator of care provided by the NHS) and the commissioner of the care they provided for RK (or its successor organisation). The Trust should also share any action plan they create with Monitor (the financial regulator of NHS foundation trusts).

136. Each organisation should carry out and share the results of their review within two months of the date of the final report. Any action plans should be prepared and shared within three months of the completion of the review. Regular updates on progress against the action plans should be shared with every organisation with which the action plan is shared.

[6] The Department of Health has agreed to pay £200 on behalf of the former PCT.

Conclusion

137. This is a sad tale about a man who was dying, and who wanted to move back into his own home, who was ultimately denied that opportunity. That denial was the result of a failure by several public organisations to properly consider RK's circumstances in the light of new law and evolving practice. We have asked the organisations involved to take steps to put things right, as far as possible, for TK – and to make sure that the correct steps are taken where patients in RK's position are concerned in future. We hope that these unhappy events will not be repeated.

Dame Julie Mellor, DBE
Parliamentary and Health Service Ombudsman

Dr Jane Martin
Local Government Ombudsman

February 2014