

A report by the Health Service Ombudsman
and the Local Government Ombudsman about
the care and support provided to a person with
Down's syndrome

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Session 2010-12

Presented to Parliament pursuant to
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Foreword

I am laying before Parliament, under section 14(4) of the *Health Service Commissioners Act 1993* (as amended) this report of a joint investigation which I conducted as Health Service Ombudsman for England with the Local Government Ombudsman. The complaint is about Northumberland, Tyne and Wear NHS Foundation Trust (the NHS Trust), Newcastle City Council (the Council) and the Coquet Trust. My reason for laying this report before Parliament is to allow the joint investigation report to be in the public domain.

This report tells the story of Mr J, who was an active, outgoing and sociable man. He had Down's syndrome. He lived independently in rented accommodation with his wife. The Council, latterly through the Coquet Trust, provided day-to-day support to Mr J and his wife to help maintain their independence. In 2005, owing to concerns about a significant deterioration in his skills and health, Mr J was admitted to hospital for a five to six week assessment. Mr J remained in hospital for seven months, some five of those after he had been declared ready for discharge. Mr J was discharged into inappropriate locked accommodation, which he only left following his death 10 months later. Mr J was 53.

Mr J's brother, Mr K, complained about the care provided to Mr J. My joint investigation with the Local Government Ombudsman found significant failings on the part of both the NHS Trust and the Council which meant that they were unable to demonstrate that Mr J's basic human rights, to liberty and to family life, had been given appropriate consideration when decisions were being made as to his care needs. There was no properly co-ordinated and documented health and care plan for Mr J. No one from the public bodies took a key leadership role and so there was no one with an overall view of Mr J's character and abilities, his family background, his needs and

the services he was receiving. There was no one to represent Mr J's interests and wishes and drive matters forward.

The NHS Trust failed to review and document Mr J's capacity to consent and the reasons for his continued inpatient status, contrary to guidance specifically designed to protect those in a similar position to Mr J. The NHS Trust also failed to involve Mr K and Mr J's other siblings in Mr J's care planning, so decisions were taken which did not take account of the family's previous involvement in Mr J's life.

Whilst he was in hospital, the Council decided to reduce the support hours available to Mr J. This had a significant impact on the amount of contact he had with his wife. The Council therefore demonstrated a disappointing and unacceptable disregard for Mr J's relationship with his wife and his wellbeing. The Council effectively abandoned their duty to actively seek to resolve Mr J's urgent housing need for his discharge from hospital. Against published guidance, the Council failed to review and record why Mr J was effectively being detained in unsuitable locked accommodation and they failed to take urgent action to find suitable accommodation. They failed to involve Mr J's family sufficiently in Mr J's care planning.

We found that the failings by the public bodies resulted in injustice to Mr J and his family, and we therefore found that Mr K's complaint about his brother's care was partly justified. The NHS Trust and the Council have accepted our recommendations to remedy the injustice.

The remedies include an acknowledgement and apology. The NHS Trust and the Council will also pay compensation to Mr K, as the family's representative. Mr K has told us he will donate the money to charity. Although the Local Government Ombudsman and I recognised that there have been

changes in the legislative framework since the events of this case, which if complied with should mean the failings described in this report should not be repeated, we did not see the existence of the framework as sufficient reassurance that lessons will be learnt. Therefore, we recommended that the NHS Trust and the Council prepare, share and update progress on an action plan showing what they have done (or will do) to prevent recurrence of their failings. They have agreed to do this.

It is shocking that the events described in this report happened in the 21st century. By putting this report in the public domain I hope the lessons from Mr J's story will be understood by public bodies and thereby help to drive improvements in public services.



Ann Abraham
Parliamentary and Health Service Ombudsman

November 2011

Introduction

1 Mr K's complaints span the remits of the Health Service Ombudsman and the Local Government Ombudsman. We both agreed that a joint investigation leading to the production of joint conclusions in one report seemed most appropriate. Mr K agreed to this approach. This report sets out our findings, conclusions and recommendations with regard to those aspects of Mr K's complaints which we agreed to investigate.

The overarching complaints

2 Mr K complained about the care and treatment provided to his late brother, Mr J. Mr J had Down's syndrome. From 1989 onwards, with support provided by Newcastle City Council (the Council) through the Coquet Trust,¹ he had lived independently in rented accommodation in the community; and he lived from 1992 onwards with his partner, Mrs N, whom he married in 1996. In November 2005, owing to concern about significant deterioration in Mr J's skills and health, he was admitted to Northgate Hospital, managed by the Northumberland, Tyne and Wear NHS Foundation Trust² (the NHS Trust), as an informal patient for assessment. Mr J remained in hospital for seven months, during which time he was diagnosed with dementia and epilepsy and was kept on a ward which was often locked, because of concerns about patient safety. When Mr J left hospital in June 2006, his previous home was considered unsuitable, and so he and his wife were placed in temporary accommodation (a self-contained flat at an elderly persons' care home). The flat was also kept locked to restrict Mr J's access outside, on the grounds of safety. Mr J remained there until 7 April 2007 when he was admitted to an acute hospital with a chest infection. Mr J

sadly died there, on 9 April 2007, of pneumonia. He was aged 53.

- 3 Mr K complained that a failure by the NHS Trust, the Council and the Coquet Trust to provide Mr J with appropriate support, or to consult appropriately with his family about his condition, meant that important information about Mr J's character, abilities, needs and preferences had not been taken into account when assessing what care and treatment was appropriate. This had exacerbated the deterioration in Mr J's condition and health. Mr K said that, as a direct consequence of that failure, Mr J had been inappropriately admitted to Northgate Hospital, wrongly diagnosed and inappropriately detained against his wishes. He said that the family believed that, had Mr J received appropriate support and care, he would still be alive.
- 4 Mr K also complained that previous investigations of his complaint had not addressed all his concerns or acknowledged the extent of service failure. In particular, that all three bodies had not addressed his contention that Mr J had been discriminated against because of his disability, in that, owing to his Down's syndrome, false assumptions had been made about his condition and abilities. Nor had they addressed his contention that both Mr J's and his family's human rights had been abused, in that Mr J had been denied his right to liberty, and he and his family had been denied the right to respect for his private and family life.
- 5 Mr K made a wide-ranging number of complaints to the bodies concerned and to us, which covered most aspects of Mr J's care and treatment. Many of the complaints were addressed by all three bodies in the earlier

¹ A non-statutory organisation contracted by social services to provide support to Mr J.

² The NHS Trust (formerly Northgate and Prudhoe NHS Trust) was formed on 1 April 2006.

stages of the complaints procedure, and others had not been put to the bodies previously, and it would not therefore be appropriate for us to address them in this report. For clarity, therefore, we set out below the specific aspects of Mr K's complaint that we have investigated.

Mr K's complaint about the NHS Trust

6 Mr K complained that the NHS Trust's failure to communicate appropriately with Mr J and his family meant that important information had not been taken into account. Consequently:

- Mr J had been discriminated against because of his Down's syndrome. No account had been taken of his communication difficulties, and instead, assumptions had been made about his abilities and preferences. As a consequence, he had not been properly assessed; he had been misdiagnosed with dementia when he was, in fact, depressed and suffering from the effects of medication given him to treat epilepsy; and he had been deprived of any choice.
- The care and treatment provided to him had been detrimental and had exacerbated his deterioration, depression and dependence on others. It had also been detrimental to family relationships, and thereby caused distress.
- The NHS Trust had been the wrong place for Mr J. He had been detained against his wishes, and therefore in contravention of his human rights to enjoy family life and to liberty. Throughout Mr J's admission the NHS Trust (particularly through the actions of medical staff, Dr A and Dr B) had failed to address Mr K's concerns. As a result, Mr J had endured a miserable time in hospital.

- Mr J's family's rights had been overridden – they had been excluded from the decision-making process in respect of Mr J's care and treatment.
- 7 Mr K also complained that the NHS Trust had not dealt adequately with his complaints, in that they had not fully addressed these issues.

Mr K's complaint about the Council

8 Mr K complained that social services had similarly failed to communicate with Mr J's family, and that important information about Mr J had accordingly not been taken into account. A failure to provide appropriate care and support, and to actively promote Mr J's best interests, before, during and after his stay in hospital had exacerbated the deterioration in Mr J's condition, skills and abilities. In particular, social services had failed:

- To provide appropriate support or educational, leisure and work activities. Consequently, Mr J's loss of skills had been exacerbated and his distress, depression and dependence on others had increased.
- To act in Mr J's best interests by securing a timely discharge for him, or by challenging the view that he should not have a short holiday with his family.
- To pursue suitable accommodation. Following Mr J's discharge to unsuitable temporary accommodation his liberty and contact with his family had remained restricted.
- To communicate effectively with Mr J's family, or to facilitate Mr J's communication with them, thereby excluding them from decisions.

Mr K's complaint about the Coquet Trust

- 9 (Mr K's complaint was dealt with as part of the complaint about the Council as they commissioned these services.) Mr K complained that:
- there had been a failure to communicate effectively with Mr J's family prior to his admission to hospital;
 - there had been a failure to provide adequate care and support prior to, during, and after, his stay in hospital; and
 - support workers had failed to facilitate Mr J's communication with his family following his discharge.
- 10 Mr K further complained that, in responding to his complaint, the Council had not properly addressed his concerns.

The Ombudsmen's remit, jurisdiction and powers, and the basis for our determination of the complaints

- 11 We have set out in Annex A our respective remits and relevant powers. Annex B provides a detailed explanation of how we determine complaints that injustice or hardship has been sustained in consequence of service failure and/or maladministration. This explanation includes full details of the general and specific standards that we apply, including disability and human rights considerations, and the specific guidance and legislation relevant to the matters under investigation in this case.
- 12 At the time relevant to these events, the Department of Health (DH) had published a national strategy and objectives for improving the lives of people with learning disabilities, as

well as guidance to all health and social care providers as to what the expectations on them were (Annex B, paragraph 26). A key objective was '*To enable people with learning disabilities and their families to have greater choice and control over where and how they live*'. The subsequent guidance providing a framework for effective mental health care required service providers to draw up a care plan, in consultation with the service user, their carers and families, which set out the service user's needs, the care to be provided, and also to identify a key worker to monitor and co-ordinate care.

- 13 Subsequently, in 2004, following a European Court of Human Rights ruling in a specific case (the Bournemouth case³), legislation and guidance were introduced, applicable to both health and social care services. This expressly intended to make sure that no one could be admitted as an informal patient to a mental health hospital and then be detained there without any documented record of the individual's initial consent to admittance, of regular reviews of their consent status, and of the reasons as to why they should remain in the institution. The DH guidance also highlighted the importance of involving family, friends and carers in care planning for the individual requiring mental health care, of keeping them appropriately informed, and of helping patients to retain contact with family and friends.

This investigation

- 14 During this investigation our staff have examined the available relevant documentation from the NHS Trust, including Mr J's medical records and information about the attempted local resolution of the complaints. We have

³ *HL v the United Kingdom – 45508/99* [2004] ECHR 720 (5 October 2004).

also considered papers from the Council and the Coquet Trust: social services assessments of Mr J; correspondence with the Coquet Trust regarding the level of support that Mr J required; daily carers' notes both prior to and after Mr J's admission to hospital in November 2005; Mr J's housing file; and the attempted resolution of the complaint by the Council.

- 15 We have taken account of Mr K's and the family's extensive comments, as set out in his correspondence and at interview. These have been set out in some detail in Annex C as we believe that they provide a helpful context, in terms of giving both some insight into Mr J's character and abilities as the family knew him, and also a better understanding of the family's experience and concerns.
- 16 We have also considered the written comments of the NHS consultants named in Mr K's complaint, namely Dr A and Dr B, and have set these out in some detail in Annex D, together with the further information provided by the NHS Trust in response to our enquiries.
- 17 We obtained specialist advice from two professional advisers: a Consultant Psychiatrist with a specialism in Learning Disabilities (the Psychiatric Adviser) and an experienced senior nurse (the Nursing Adviser). Their advice and comments are set out in more detail in Annex E. Our professional advisers are specialists in their field, and in their roles as our advisers they are completely independent of any NHS body.
- 18 The draft report was shared with Mr K, the NHS Trust, the Council and the Coquet Trust. Their comments on the provisional findings were also taken into consideration before we reached our final conclusions.

- 19 In this report we have not referred to all the information examined in the course of the investigation, but we are satisfied that nothing significant to the complaint or our findings has been omitted.

Summary of our decisions

- 20 Having considered all the available evidence related to Mr K's complaint and taken account of the clinical advice we have received, we have reached the following decisions.

Overall

- 21 Mr J's health and social care needs were clearly complex and required that he should have, in line with the relevant guidance, a properly co-ordinated and documented health and care plan, with an identified key worker to monitor and co-ordinate all of the services, to ensure that information was appropriately shared, and to ensure that Mr J's and his family's wishes were taken properly into account. The role of the key worker is always important, but where the person receiving the services concerned is vulnerable, that role is clearly critical. Yet that did not happen here. As a result, there was no one individual involved in Mr J's care taking an overall view and representing his best interests. Further, and possibly as a result of that significant failing, the NHS Trust, the Council and the Coquet Trust jointly failed to involve Mr J's family sufficiently in planning his care, which meant that important opportunities were missed to try to ensure that Mr J got the best out of his everyday life. Even more significantly, those bodies also failed to take appropriate steps to demonstrate that proper consideration was given to Mr J's basic human rights (specifically to liberty and to a family life) when decisions were being made as to

his care needs. As a result of those failings, opportunities were not taken to assess Mr J's needs promptly and appropriately, with due regard to his rights, best interests and wishes, and his relationship with his wife and family. This was highly likely to have had some impact on the quality of his life, and hence his well-being, in the last 18 months or so of his life. Further, Mr J's family were also wrongly denied the opportunity to contribute to his care planning, and will never now know if they could have made a difference to the quality of Mr J's life in those last months; that uncertainty is undoubtedly a cause of significant and ongoing distress to Mr K and the rest of Mr J's family.

Complaint about the NHS Trust

22 We uphold the complaint about the NHS Trust in part. We found that there was significant service failure in terms of failing to follow guidance and best practice and to:

- document the assessment of Mr J's capacity to consent both to his admission and to his continued stay in hospital, and thereby show that Mr J's human rights were being adequately protected;
- involve Mr K and the family more fully in Mr J's care planning (including contacting Mr J's family prior to Mr J's admission to hospital) to ensure that Mr J's wishes and best interests were fully taken into account in the care and treatment he received.

However, we found that the clinical care and treatment provided by the NHS Trust, including the decision to admit Mr J to hospital were, on the whole, reasonable, as was the handling of Mr K's complaint.

Complaint about the Council

23 We uphold the complaint about the Council in part. We found serious service failure by the Council, in that they did not:

- document adequately why Mr J had been effectively detained in unsuitable, locked accommodation for too long, and thereby demonstrate that his human rights were given proper consideration;
- take appropriate and timely action to find permanent suitable accommodation for Mr J and his wife;
- promote sufficiently Mr J's contact with his family.

We did, however, find that the investigation of Mr K's complaints had generally been thorough, and that the recommendations that had been made during the statutory complaints process to remedy shortcomings had been implemented.

Complaint about the Coquet Trust

24 We do not uphold the complaint about the Coquet Trust. It is clear that the Coquet Trust had been fully aware of the key importance to Mr J of regular contact with and support from his family. Following his discharge to the care home in particular, they had supported Mr J to have daily telephone contact with his family and had updated the family daily on Mr J's well-being over the previous 24 hours.

25 We have also found no evidence that the Coquet Trust demonstrated serious failings in carrying out their caring role. Although we found that the Coquet Trust's record keeping had sometimes been poor, the records made in the period just before Mr J's death showed that

the staff did contact the GP and the community nurse about Mr J's health at that time, and that neither the GP nor the nurse had expressed any particular concerns. We are therefore satisfied that there is no evidence to suggest that poor care or monitoring by the Coquet Trust's staff contributed to Mr J's death, as Mr K believed.

The Investigation

Background and key events

26 (A more detailed chronology is provided at Annex F.) Mr J had Down's syndrome. He was an active, outgoing and sociable man who from 1989 onwards, had lived independently in the community; from 1992 onwards this was with his partner, Mrs N (who also has learning disabilities), whom he married in 1996. Day-to-day support to help Mr J and his wife maintain their independence in rented accommodation was provided by the Council; from 1995 onwards this was through a contract with the Coquet Trust, who provided local support workers. Mr J's mother died in 1998. In 2003 one of the carers who had been providing support for Mr J for a long time, and whom Mr J considered a friend, moved away from his role as Mr J's carer. Until 2003 Mr J had had a work placement in an office doing photocopying two days a week, but this was terminated when his tenure ended and it was considered that Mr J could no longer cope with it. (No other placements were found for Mr J, other than helping out for a few hours a week in the Coquet Trust's office, until the autumn of 2005.)

2004-05

27 In April 2004, due to concern about changes in Mr J's behaviour and a deterioration in his abilities, the Coquet Trust requested funding to increase the support hours being provided to Mr J, which were then 15 hours per week (and 15 hours for Mrs N). During 2004 a consultant clinical psychologist, who had assessed Mr J on several occasions since 1998, concluded that Mr J could be suffering from a loss of skills associated with a process of early ageing.

- 28 In December 2004 DH issued interim guidance on the Bournemouth case, which was intended to protect vulnerable individuals against the risk of arbitrary deprivation of liberty.
- 29 During the rest of 2004 and much of 2005 social services and the Coquet Trust corresponded about Mr J's support needs, with the latter pressing social services to fund extra hours in response to the continuing decline in Mr J's skill levels and functioning. They raised particular concerns about his mobility problems (increasing unsteadiness and his wife had reported that he had had falls), changes in mood and memory difficulties, which meant that many tasks took longer for Mr J to complete and that he needed repeated prompting. In October 2005, after Mr J had recently required police assistance to return home after becoming confused and anxious in public without support, various further assessments of Mr J's needs and abilities were carried out. This led to a recommendation by an occupational therapist (OT) that Mr J required ground floor accommodation and led to social services agreeing to fund 21 hours support per week for Mr J (and the same for Mrs N).
- 30 On 2 November 2005 Mr J's GP made an urgent referral to the NHS Trust because of concern about a significant general decline in Mr J's health and condition; he noted a recent history of falls and brief spasms (myoclonic jerks) suggesting epilepsy. A Consultant Psychiatrist (Dr A) saw Mr J on 11 November. Her initial assessment was that Mr J was probably suffering from depression, for which she prescribed medication. However, as the changes in Mr J's condition might be caused by a number of other factors, she also asked for a nurse from the community learning disability team (CLDT) to visit Mr J at home, made referrals for a CT scan and an electroencephalogram (EEG, which tests

- brain activity). She also requested an application form for Mr J and his wife to be rehoused.
- 31 On 14 November Dr A wrote to Mr J's GP. She noted that Mr J's wife had reported that he had fallen down several times and that at the appointment Mr J '*looked the picture of misery*'. He could not give any account of himself and had '*marked psychomotor retardation*'. Although she noted that Mr J had regular contact with his brother, Mr K, she also commented that because Mr J's wife had not attended the appointment, she had had to rely on what his carers could report. Dr A said she would see Mr J with his wife in two weeks. She detailed the medication she had prescribed, and said that an EEG would be arranged as soon as possible. If there were urgent concerns an earlier appointment could be arranged. Dr A copied her letter to the Coquet Trust, the CLTD nurse and Mr J's social worker.
- 32 Dr A saw Mr J with his wife on 16 November and admitted him that day as an informal patient to Northgate Hospital for a five to six week assessment. She recorded that Mr J and his wife had, after lengthy discussion, agreed to the admission. There was no record of any assessment of Mr J's capacity to consent to admission being carried out at this time. (Hospital forms completed from 22 November onwards relating to patient consent to share information about their health and treatment all said that Mr J did not have the capacity to consent.) Following admission Mr J had a variety of assessments and tests including a CT scan.
- 33 A meeting set up in line with the Care Programme Approach (CPA – Annex B, paragraph 29) was held on 1 December; Mr J's social worker was sick and unable to attend. Mr K and Mr J's wife attended the meeting. Dr A told the meeting that Mr J had cognitive decline and that she was proposing that Mr J's care be transferred to Dr B, a different Consultant Psychiatrist. The nursing note prepared for this meeting (and the notes prepared for subsequent meetings) recorded that Mr J wished to be discharged to live with his wife. The meeting noted that social services needed to find appropriate accommodation for Mr J and his wife as soon as possible.
- 34 On 29 December Mr K raised a large number of concerns with hospital staff about Mr J's care and treatment on the ward, including the decision to put Mr J on a soft diet (he considered it to be unnecessary and to be causing Mr J's weight loss); Mr J's restricted lifestyle and lack of activity, which the family believed was exacerbating his decline and depression ('*the ward was like a prison*'); and the lack of communication with Mr J's family. Mr K asked when Mr J would be discharged and expressed dissatisfaction that social services were not promoting Mr J's best interests. He complained about the decision that had been taken to stop prescribing antidepressants for Mr J, and said that Dr B had not said why she had not asked him for information about Mr J. The hospital records show that these matters then continued to be raised with the staff over the telephone by Mr K and Mr J's other siblings, when they called to ask how Mr J was, or when visiting.

2006

- 35 On 10 January 2006 Mr J, Mrs N and the OT visited Mr J's former home in order to carry out an assessment. The OT completed a detailed assessment in which she noted that not only was the flat on the first floor, reached via a 14-step stairway, but the interior was also uneven with stepped access into several rooms, which meant that there was a high risk of Mr J

- falling. The OT considered that it was too dangerous for Mr J to return there.
- 36 At a difficult CPA meeting held on 12 January⁴ Mr K was told that Mr J had dementia and epilepsy and needed 24-hour care, but that he could leave hospital as soon as social services could provide appropriate support. (Staff did not invite Mr J's family to subsequent CPA meetings, but it was noted in the files that they should be kept informed of what had been discussed and agreed. Apparently at Mr K's instigation, Mr J was subsequently assigned an advocate from the advocacy project Skills for People, who attended the CPA meetings from 9 February onwards.)
- 37 Around this time, to reduce the impact on patient care on the ward, the NHS Trust introduced some telephone and visiting guidelines for Mr J's family, which included restricting the number of telephone calls to Mr J's ward to twice a day, and the family's time on the ward to two hours a day. However, the NHS Trust did say that the family could take Mr J off the ward for an unspecified amount of time when they wished.
- 38 On 16 January it was confirmed at a CPA meeting that Mr J could be discharged with support, but that he should not return home and that temporary accommodation was not in his best interests. The meeting also again confirmed that lead responsibility for finding appropriate accommodation rested with social services. On 31 January Your Choice Homes (the Council's local housing provider – Annex B, paragraph 37) sent Mr J a medical priority form to complete regarding his application for housing.
- 39 On 6 February Mr J's wife and his new social worker visited him and talked about accommodation; Mr J said that he wanted to leave and live with Mrs N. Later that day the social worker called the housing department to ask how long it was likely to take before appropriate permanent housing would be available, and was told at least six months. In the light of that, at the CPA review on 9 February, it was decided that, given the time that Mr J had already spent in hospital, an interim placement would be more beneficial to him than a lengthy wait for a permanent one. The Coquet Trust staff helped Mr J to complete the housing medical priority form and Your Choice Homes received the completed form on 22 February.
- 40 Meanwhile, interim accommodation in the form of a first floor flat at the care home (a home for the elderly) had been identified which would become available from 8 March. An OT visited the flat on 16 February and identified the adaptations (grab rails in the bathroom and a shower chair) that would need to be made before Mr J and his wife could move in. (Mr J and his wife were subsequently taken to view the flat on 23 March.)
- 41 On 3 March Mr K made formal complaints about the NHS Trust, social services and the Coquet Trust (according to Mr K, this was in the hope of accelerating Mr J's move out of the hospital into permanent appropriate accommodation).
- 42 Mr K received a response to his complaint from the NHS Trust on 12 April, but remained dissatisfied and entered into further local resolution with the NHS Trust, before putting his complaint to the Healthcare Commission (the body which at the time oversaw the second stage of the NHS complaints

⁴ Mr K became agitated and was asked to leave.

- procedure). He was also unhappy with the social services' response and in July, asked social services to carry out a Stage 2 investigation of his complaint (Annex B, paragraph 41). (His complaint about the Coquet Trust was included within that complaint.)
- 43 On 15 May a further physiotherapy assessment found that Mr J's balance and mobility had deteriorated significantly over the preceding few months and that he now had a very high risk of falling. The OT found that although Mr J's physical abilities were fluctuating daily, he would ultimately need full use of a wheelchair and a mobile hoist in the bedroom. (This meant that the permanent accommodation being sought would need to take account of these future needs.)
- 44 In the meantime, in response to Mr K's unhappiness with the proposals for Mr J's future accommodation, Mr J had been allocated an independent mental capacity advocate (IMCA). Her role was to consider Mr J's best interests and ascertain if his own wishes, feelings and rights were being considered in the decision regarding where he would live following his discharge from hospital. In her report (dated 17 May) she concluded that, although given his diagnosis Mr J's condition was unlikely to improve, and he would no longer be able to go out independently, he was not benefiting from being in hospital, separated from his wife and unable to lead a life that included enjoying some of his interests in a familiar environment, with support staff that he knew. The IMCA accordingly supported the move to the care home. She said that Mr J should be discharged as soon as possible to temporary accommodation, as this would enable him to live with his wife, but she also stressed that it was important that the search for a ground floor flat continue.
- 45 On 12 June, once the required adaptations had been completed, Mr J moved to the care home with his wife, where he was provided with 24-hour support by live-in carers provided by the Coquet Trust. Around this time Mr J lost his medical priority for housing because he had not bid for any properties. On 20 July the Coquet Trust wrote to Your Choice Homes explaining that Mr J had been unable to bid for a property because he had been ill and in hospital. They asked for his medical priority to be reinstated.
- 46 On 21 July Dr B wrote telling Mr J's GP that Mr J had settled well at the care home and that 24-hour support appeared to be working. Mr J was still able to join in some activities in the community, such as swimming, and he was still able to walk within the grounds but otherwise needed a wheelchair outdoors. No further myoclonic jerks had been recorded. On the whole he slept well. He had lost some weight but was still a healthy weight. He was occasionally doubly incontinent at night.
- 47 Dr B also noted Mr K's request that Mr J and his wife stay with him for a few days. She advised that any major changes to Mr J's then current daily routine would significantly affect his functioning and emotional well-being. Whereas in the past a holiday might have been a stimulating and positive experience, she believed that it was now likely to cause him undue stress. (Social services subsequently wrote to Mr K on 25 August saying that, in the light of that medical advice, they felt that it would be better if Mr J continued to enjoy day trips with the family, but did not at present commit to overnight stays.)
- 48 In the meantime, on 4 August, Mr J's social worker wrote to Mr K about his daily contact telephone call with Mr J. He said that the Coquet Trust support staff were concerned

that the daily calls (which they initiated in order to support Mr J's contact with his family and to update them on Mr J's well-being in the previous 24 hours) often lasted up to an hour, but were in the main not spent with the family talking to Mr J or Mrs N, but with the family making complaints to the staff about past and present support arrangements. That took staff away from caring for Mr J. He asked that any such complaints should be addressed to him, or to the Coquet Trust management. He also referred to Mr K's request that Mr J should ring at a set time each day, saying that there had to be some flexibility around the arrangements to suit Mr J's needs.

- 49 On 8 August Mr J's medical priority for housing was reinstated.
- 50 On 18 October another consultant psychiatrist took over Mr J's care. Mr J's condition continued to decline, and Mr K continued to express dissatisfaction to the Coquet Trust with Mr J's care and support, and about the difficulty the family had in reaching Mr J by telephone when they wished to, as the flat had no landline. (Mr K's home was about 80 miles from where Mr J lived, and of necessity, therefore, their most regular contact was by telephone.)
- 51 On 27 October and 2 November Your Choice Homes offered properties for consideration for Mr J and Mrs N. Social services and the Coquet Trust staff refused these on Mr J's behalf, the first because the bedrooms were too small to enable staff to be able to meet Mr J's care needs (including the use of a bed hoist when required), and the second on the advice of the community nurse and the OT that it did not meet Mr J's needs and the required adaptations would take too long. Neither Mr J nor Mr K were told about these offers. On 13 November Mr J's medical priority for rehousing lapsed

again because no interest had been expressed in the properties offered. There is no evidence to suggest that Your Choice Homes notified Mr J or anyone else involved in his care of this. No further properties were offered or considered subsequently.

2007

- 52 Mr J's GP attended him on 4 April 2007 because the Coquet Trust staff were concerned about noises in Mr J's chest. Mr J's chest was found to be clear. The GP considered that the chest noise could be due to Mr J not swallowing his food properly.
- 53 Mr J became unwell and was admitted to hospital on 7 April for intravenous medication, as his swallowing difficulties prevented him from taking it orally. Sadly Mr J died there from pneumonia on 9 April.

2008

- 54 The findings of the Stage 2 complaint to social services were issued in January 2008 and on 28 April the Council responded to the Stage 3 findings. Mr K remained dissatisfied with the responses he had received and subsequently complained to us.

Mr K's comments

- 55 It is very evident from Mr K's account in Annex C and in his other representations that there was a strong bond between Mr J and his family. Mr K was clearly passionate in his desire to see that his brother got the most he could out of his daily life, and remains convinced that the family were the only ones who truly knew Mr J, and recognised his full potential, talents,

and preferences. The main thrust of Mr K's outstanding complaints is that he strongly believes that the failure of the relevant service providers to recognise the special relationship that existed between Mr J and his family, and to involve them appropriately in Mr J's care, caused a chain of events that resulted in a rapid deterioration in the quality of Mr J's life and health and eventually led to his death. He considers that these important and significant matters have not yet been properly addressed.

The bodies' responses to the complaints

The NHS Trust's response

56 We offered the NHS Trust the opportunity to comment on Mr K's complaint at the outset of this investigation. The NHS Trust told us that they considered that they had followed DH's interim guidance following the Bournemouth case. They were satisfied that their policies and procedures at the relevant time had been in line with the interim guidance.

The Consultants' comments

57 Dr A and Dr B, the Consultant Psychiatrists at the NHS Trust identified by Mr K as having been responsible for Mr J's inappropriate admission to, and detention in, the NHS Trust and his misdiagnosis, sent us their own comments on the parts they played in these events. These are set out in detail in Annex D.

58 In summary, Dr A said that she remained convinced that Mr J's admission to the NHS Trust on 16 November 2005 had been in his best interests. She had witnessed a major deterioration in Mr J's condition in just a few days. It was unclear what had caused that.

There were a number of possibilities which had needed to be investigated urgently and could not be carried out effectively on an outpatient basis, and although she had considered contacting Mr K beforehand, her chief concern had been to find Mr J a place of safety that evening.

59 Dr A said that when the options had been discussed with Mr J, his wife and his carers, it had seemed that the best option had been for the community nurse to take Mr J and his wife to view the hospital, meet the staff and see whether he would be prepared to stay. The admitting officer had subsequently documented that Mr J had said that he was happy to stay. It was the admitting officer's duty to contact the next of kin; and Dr A had assumed that this would include not just Mr J's wife, but the wider family.

60 On the matter of whether Mr J had capacity to consent to his admission, Dr A said that guidance said that there should be an assumption that a patient possessed capacity until shown otherwise. Mr J had been so distraught when she saw him that she would not have been able to assess capacity at that time, but she felt that the fact that Mr J had said that he was happy to stay once he had seen where he would be sleeping and meeting the staff at the hospital supported the view that Mr J did have the capacity to consent. Dr A acknowledged that she should have documented in her notes that, had Mr J expressed a will to leave the hospital rather than be admitted, he should be assessed under the *Mental Health Act 1983* (Annex B, paragraph 22), but that she had not done so at the time because of the urgency of the situation.

61 Dr A went on to say that she had not made any definite diagnosis as to what was causing the deterioration in Mr J's functioning. However, as the information she had indicated the possibility that he might be severely depressed, she had prescribed antidepressants. However, Mr J had subsequently become very sleepy and had low blood pressure, which were both possible side effects of the medication, and so she had discontinued it so that baseline assessments of Mr J's blood pressure, mental state and fit frequency could be carried out. Dr A concluded that she believed that she had made strenuous efforts to ensure that Mr J had not been discriminated against; she had done all she could to exclude any underlying physical and treatable cause of his deterioration.

62 Dr B said that it was sometimes difficult to determine whether symptoms were a consequence of depression or dementia, but it had been established that Mr J's symptoms were due to dementia. Given that diagnosis, there had been no clinical reason to restart the antidepressant medication. The speech and language therapist (SALT) had considered a soft diet necessary to reduce the risk of Mr J choking or aspirating food, which could have been fatal. She concluded that the multidisciplinary team had had Mr J's best interests in mind, and that his needs had been addressed as they had emerged.

The Council's response

63 We wrote to the Council at the outset of the investigation to offer them the opportunity to comment on Mr K's complaint. As the Coquet Trust are a voluntary body, funded by the Council, and were providing services contracted by the Council, the Council responded on behalf of both bodies. The Council told us that

the complexity of Mr J's needs had made his home unsuitable to live in after his discharge. The decision to use the care home had been taken because there had been an urgent need for Mr J to be discharged and reside with his wife: that decision had been a multidisciplinary decision agreed with health professionals. It was accepted that this was not an ideal solution, but no other accommodation had been available; residential accommodation would not have been appropriate because Mr J had been married and wished to live with his wife.

64 The flat at the care home was on the first floor and, although normally accessed by a lift, there were stairs close by: the flat was kept locked because there was a risk of Mr J falling and wandering.

65 Mr J's family had had to sign in and out when they visited because of fire regulations. Mr K's unhappiness with this was known, and Coquet Trust staff had done what they could to mitigate his dissatisfaction. In a letter to Mr K of 4 August 2006 the Council had stated that they were *'committed to working constructively to ensure the maintenance of positive communication'*.

66 With regard to Mr J's care, the Council said that a side effect of his medication had been weight loss, which had been monitored by health professionals. Coquet Trust staff had been given appropriate training to manage the situation. Mr J's condition had also made him susceptible to infections, such as pneumonia. Mr J had received extensive support from the Council, and appropriate services such as occupational therapy had been called in when necessary. During Mr J's stay in hospital the Council had continued to commission eight hours of care per week from the Coquet Trust to promote

- Mr J's emotional well-being by enabling his wife to visit him. Following his discharge from hospital, 112 hours of care, plus waking nights (that is, 24-hour) care had been provided.
- 67 Turning to the handling of Mr K's complaint, the Stage 2 investigator had not interviewed Mr K or his sister because there had been extensive communication with them between April and September 2006 about the arrangements for the investigation. Mr K had sent a substantial amount of documentation and comments, and had spoken by telephone; therefore a meeting would further have delayed matters. Mr K had made no complaint at the time about the lack of a face-to-face meeting.
- 68 There had been delays with the complaint, partly due to the sick leave of two social workers who had provided support to Mr J, neither of whom returned to work.
- 69 The Council went on to say that, in line with the Stage 3 panel recommendation, their team had met staff of the council for social care inspection (CSCI) on 29 April 2008. The agenda had included the discussion of individual (serious) cases, including Mr K's complaint.
- 70 The Council had also taken action in response to the other Stage 2 and Stage 3 recommendations. This had included:
- carrying out significant training across the learning disability service;
 - continued work with the CLDT, Dr B and the NHS Trust to develop individual support plans for all users of services with a diagnosis of dementia; and
 - a review of policies and procedures.
- 71 The Council said that team managers and social workers had been working in partnership with housing associations, private landlords and housing providers on Mr J's accommodation needs. All had been aware of Mr J and his wife's housing requirements (*'ground floor flat or bungalow with a maximum of one or two steps on entry, preferably with a level access shower in situ and that two bedrooms were essential'*) and had been asked to report to managers if suitable properties came up. This was normal practice. Social workers were seeking housing solutions and would contact housing providers. If a solution arose that was not suitable for a particular service user, the details would be shared with the rest of the team to ensure that other users' needs were taken into account.
- 72 The Council said that Mr J's particular needs had restricted the number of housing options. This was not inactivity, or missed opportunity on the Council's part and great effort had gone into trying to support Mr J and his wife at the care home, particularly given that Mr J's health was fluctuating so much, leading at times to the need for an increase in staffing. That had meant, however, that at those times the focus had been on meeting Mr J's immediate health needs, rather than on actively pursuing permanent housing. The Council commented that Mr J had not nominated a specific individual to make housing bids on his behalf.
- 73 In response to our subsequent enquiries, the Council told our staff that 41 two-bedroom ground floor flats had been allocated in the Heaton and Byker areas between February 2006 and April 2007, of which eight had been adapted; the remaining properties had had the potential to be adapted. There would also have been other properties advertised throughout the city during this time. However, the majority of these properties, even those that had been adapted, were unlikely to have been regarded as a suitable environment to meet Mr J and Mrs N's needs, some, for example, were within a

large multistorey block. Nevertheless, if Mr J or his representatives had expressed an interest in a property, the Your Choice Homes OT would have assessed whether it was adaptable, prior to an offer being made.

74 When an adapted property became empty a housing officer would obtain a list of potential tenants. This was how two offers were made to Mr J. Regarding the first, it was recorded that housing staff had met staff from social services and the Coquet Trust who advised that the bedrooms were too small. Regarding the second, the records indicated that staff and the OT had concluded that it was unsuitable. The Council said that although they were declined, the two properties had appeared to meet the basic requirements.

75 Regarding the DH interim guidance following the Bournemouth case (Annex B, paragraphs 32 to 34), the Council said that they had no evidence of issuing their own separate guidance to staff. However, from January 1998 social services had held discussions, including representatives of local NHS bodies, about the implications of the ruling. The NHS Trust had asked regional medical officers to review all existing cases and new admissions to establish if informal patients should be sectioned. In March 1999 social services held joint training which dealt with the implications for mental health teams, the CLDT and NHS Trust staff. In May 2005 approved social workers had attended training, and discussions had continued in the Council's approved social work forum. Thereafter approved social workers had been alerted to advice from Newcastle, North Tyneside and Northumberland Mental Health NHS Trust, which dealt with the Bournemouth case and its implications. The Council said that they were satisfied that they had followed the DH guidance.

Professional advice received

76 The Psychiatric Adviser's detailed comments (in Annex E) identify the following key points. With regard to Mr J's admission to hospital, Dr A had faced a difficult situation and, although the admission had not been documented in line with the relevant guidance, and Mr J's family had not been contacted and consulted as they should have been (both before and throughout his admission), which were both serious matters of concern, nevertheless the decision to admit, in itself, seemed reasonable on the available evidence. The Psychiatric Adviser went on to say that the records indicated that Mr J had been admitted because of his distress and because of the concern that he might have a life-threatening condition. In those circumstances it would have been poor practice to have sent Mr J home. He also confirmed that it was appropriate for Dr A to suggest that a successful and timely scan was more likely if Mr J was supported from within a specialist learning disability unit; any other urgent assessments would also be easier to arrange.

77 The Psychiatric Adviser also noted that Mr J had been judged ready for discharge on 12 January 2006, just eight weeks after admission. The assessment process had therefore taken just two weeks longer than Dr A had originally anticipated. The key difficulty had been the further five month period it had taken to find and equip suitable accommodation. It was during that delay that serious problems had begun to arise for Mr J in terms of his restricted contact with his wife and family, which would have been distressing for him. Against that background the decision not to allow Mr J (after his discharge) to visit his brother for a short period was unsatisfactory.

78 However, the overall level of clinical treatment that Mr J had received from the NHS Trust had not fallen below acceptable standards, and there was no evidence to suggest that Mr J had been discriminated against because of his disability in the way described by Mr K. Namely, there is nothing to show that assumptions had been made about Mr J's symptoms, or that no account had been taken of his communication difficulties. Appropriate investigations had been carried out to identify possible causes of Mr J's deteriorating condition, and there was enough evidence in the medical notes to confirm that he was suffering from dementia.

79 The Nursing Adviser, although concerned about the poor record keeping of the Coquet Trust's staff, said that she had found nothing to suggest that, in the days immediately preceding Mr J's death, that they had failed to pick up on indications that a serious or fatal decline in his health was imminent.

Findings

Overall

80 It is not at all surprising that, even though their complaints have previously been investigated in some depth, Mr J's family should remain convinced that something must have gone badly wrong in the care and treatment provided to their brother, which has not yet been fully addressed. If any individual who was admitted to hospital for a few weeks' assessment subsequently remained there for seven months, some five of those **after** they had been declared ready for discharge, and was then released into inappropriate locked accommodation which they only left due to their death some 10 months later, it would raise serious questions. Where the

individual concerned is a highly vulnerable adult, with deteriorating health, whose quality of life depends heavily on being in a suitable environment with the care and support of his family and carers, those serious questions demand answers.

81 The major failure we have identified was the lack of any properly co-ordinated and documented health and care plan for Mr J, with an identified key worker to monitor and co-ordinate those services and to ensure, not just that information was shared fully and appropriately between all of those involved, but also that Mr J's and his family's voices were clearly heard. That did not happen – with worrying consequences for both Mr J and his family.

82 The fact that no one had taken that key leadership role meant that not only was there no one individual with an overall view of Mr J's character and abilities, his family background, his needs and the services he was receiving, but also no one to represent Mr J's interests and wishes appropriately by driving matters forward when these were clearly not being served. This was demonstrated in the CPA meetings, where it was recognised that the NHS Trust was not a normal living environment and could not provide Mr J with the opportunities and activities available in the community, as well as the importance to Mr J of living with his wife, and yet then simply noting that it was social services' responsibility to find the required accommodation. That lack of leadership might also explain why the CPA meetings were not carried out in line with the DH guidance and the records were so poor – including the failure to complete the 'service user/carer' section (Annex E, paragraph 8).

83 That does not, however, mean that we agree with Mr K's view that the NHS Trust, the Council and the Coquet Trust should be held responsible for the deterioration in Mr J's health and abilities leading to his death. There can be no doubt that the change in Mr J's condition over a relatively short period came as a shock to his family; and the distress this caused them comes across clearly in Mr K's complaints, and indeed in the family's dealings with those involved in Mr J's care. It is also very evident that they remain convinced that Mr J was suffering from depression, which could, if treated appropriately, have been managed so that his skills and daily functioning did not decline. But it is very clear from the notes of the professionals caring for Mr J that his condition had not only been fluctuating but also generally deteriorating for some time; indeed concerns had been raised about this by the Coquet Trust staff in the two years before Mr J was admitted to hospital. We are satisfied from the clinical evidence we have seen (including the EEG and CT scan results), and the professional clinical advice we have received, that this very sad course of events had physiological origins, in other words, it had its roots in the onset of dementia and epilepsy, and was not simply due to a lack of appropriate opportunities being provided for Mr J to use and practise his skills. Further, that deterioration clearly escalated quite suddenly in the latter half of 2005, and the causes of that needed investigating. It is against that background that we have reached the conclusions below.

The NHS Trust

84 We are satisfied that the initial decision to admit Mr J to the NHS Trust was a reasonable one in all the circumstances. It is clear that

Dr A, when dealing directly with Mr J, was striving to take all of his circumstances into account including his marriage, his underlying Down's syndrome, his preferences and, especially, his safety. Whilst we appreciate that Mr K does not believe that Mr J would have consented to admission, we find Dr A's comments in this respect (paragraph 59) persuasive. In particular, we do not see that discrimination against Mr J (on the grounds of his Down's syndrome) came into play here. Rather, we note that Dr A was careful not to make assumptions and rush to a diagnosis of dementia linked to Down's syndrome, but was open to a variety of possible reasons for the deterioration, and had tests carried out to look into those possibilities.

85 We also cannot conclude that Mr J was misdiagnosed. As we have already indicated above, whilst we appreciate Mr K's strong view that Mr J was simply depressed, we find it reasonable, on the basis of the clinical evidence we have seen, to conclude that Mr J did indeed have dementia and epilepsy; and that his medication was therefore appropriate. Similarly, we take note of the Psychiatric Adviser's comment that it was reasonable to adjust Mr J's diet to take account of potential risks such as choking.

86 We have also found no fault with the NHS Trust's overall handling of Mr K's complaints. They responded to Mr K's initial complaint within a reasonable time frame; they then entered into further local resolution, changing Mr J's consultant psychiatrist as requested and drawing up an action plan with social services. They set out in their final response the outcome of the local resolution meeting (held in October 2006), as well as apologising again for identified shortcomings, and advising Mr K correctly on what further action he

could take. In essence, we have seen that the NHS Trust went some way to try to resolve the complaint and we do not conclude in all the circumstances, and with the difficult relationship which they at that stage had with Mr K, that the process followed by the NHS Trust in dealing with his complaints was inherently unreasonable.

87 However, that does not mean that the NHS Trust were fault free – far from it. We find that the NHS Trust failed Mr J in two important respects. First, there is the question of Mr J's continuing capacity to consent to staying in the hospital. Dr A has acknowledged that she should have documented her views on Mr J's capacity to consent to admission, but had failed to do so because of the urgency of the situation. Whilst we would observe that it is precisely when making urgent decisions that it is most important to document the reasons for them, we do not believe this would have made any difference on the day of admission.

88 What it might, however, have done is to prompt others, in the coming months, to review and document Mr J's capacity to consent and the reasons for his continued inpatient status, in line with the guidance issued following the Bournemouth case. That did not happen – despite the fact that that guidance was specifically designed to protect those in a similar position to Mr J and ensure that they were not inappropriately kept in hospital against their wishes – even if with the best of intentions. We consider that failure to be a major breach of guidance and therefore maladministration.

89 We note that the NHS Trust have contended that there was no overt sign that Mr J wished to leave the hospital, and that he had made no attempt to do so. They deny that he was

unhappy there, and claim that there is no evidence that he was being kept there against his will. Mr K, on the other hand, tells a different story and talks of Mr J's distress on being returned there, and says that Mr J's right to liberty under the *Human Rights Act 1998* was thereby denied. We note that the European Court was of the opinion (Annex B, paragraph 32) that the fact that an individual might not have tried to leave did not mean they were not being 'detained'. But in any event, there is clear documentary evidence of Mr J's expressed desire to leave the hospital, both in the nursing reports prepared for the CPA meetings, and in the social worker's note of his visit on 6 February 2006 (some three weeks after the CPA meeting had said Mr J was ready for discharge).

90 It seems to us that, whether it was the NHS Trust's intention or not, they had clearly given Mr J and his family the impression that only they (the NHS Trust) could say when Mr J could leave the hospital. Indeed, the fact that the NHS Trust had overall control in this matter appeared to be reinforced when Mr K was told in August 2006 that Mr J would not be allowed to visit him for a few days on the advice of Dr B, despite the fact that Mr J was by then living in the care home. We would add that we also find it surprising, given the limited number of such specialist beds available for patients, and the fact that it was generally recognised that it would be better for Mr J's well-being to be discharged and be with his wife, that the NHS Trust did not do more, once Mr J had been judged ready for discharge, to urge social services to find suitable accommodation as quickly as possible. Instead they were apparently content to let him wait for the next five months in hospital.

- 91 As we have indicated (Annex B, paragraph 18), it is not for us to determine whether the law on human rights has been breached. What we can, however, say is that the relevant DH guidance (Annex B, paragraph 32) was clearly intended to ensure that those rights were appropriately protected. We conclude that by failing to follow that guidance, the NHS Trust have failed to show that they had due regard to those rights in their dealings with Mr J.
- 92 The NHS Trust's second key failing was in their failure to involve Mr K and Mr J's other siblings appropriately in Mr J's care planning, both in line with the relevant guidance and good practice. It is evident that there were lapses in communication, and gaps in the knowledge which the NHS Trust had, and shared, about Mr J. For example, Dr A pointed out that when she first saw Mr J in November 2005 she had not been told about the community nurse's previous extensive involvement with Mr J, nor been aware of the multidisciplinary assessment in October 2005 (Annex D, paragraph 4).
- 93 In particular, however, there does seem to have been a failure to appreciate the full importance of Mr J's family in his life and, potentially, in his future. As a result, not only were the family not consulted before Mr J's admission, but decisions were made which did not take any account of the family's previous involvement in Mr J's life. The suggestion, for example, by Dr B in August 2006 that Mr J would be caused undue stress by the unfamiliar environment if he went to stay with his brother for a few days took no account of the many successful visits Mr J had enjoyed there previously. That decision not only deprived Mr J of a potentially pleasurable break, after a very long time away from his family, but clearly caused great distress on all sides. (We note, however, that that issue was later resolved as Mr J and Mrs N did subsequently spend several weeks visiting Mr K and his wife, both over Christmas 2006 and then again in early 2007.)
- 94 It is evident that, after Mr J's admission, the NHS Trust were generally aware of the family's involvement and intended to include them in the discussions about Mr J's care and treatment. Accordingly, the family was initially invited, in December 2005 and January 2006, to the CPA meetings considering Mr J's care needs. What is also clear is that Mr K disagreed with, and was distressed by, both the NHS Trust's diagnosis and the prognosis given for Mr J, and made that very clear. In such circumstances it is not, perhaps, surprising that feelings ran high at the second meeting; Mr K acknowledges that he spoke out of turn and was asked to leave. However, he was not then invited to any further meetings. That was simply not acceptable. Regardless of how difficult the relationship was to manage, it did not provide the NHS Trust with *carte blanche* to disregard the guidance and best practice and exclude the family from contributing their extensive personal knowledge and experience of Mr J into his future care planning. We note that the family were in daily contact with those caring for Mr J on the ward, and took those opportunities to press their views as to Mr J's care needs, indeed so much so that their contact had to be restricted (paragraph 37). Nevertheless, we think it reasonable for Mr K to argue in these circumstances that, had the family's views been taken into account at subsequent CPA meetings, a different outcome, or at least a more urgent solution to Mr J's accommodation needs, might have been sought.
- 95 That does not, of course, mean to say that Mr J's basic needs were being overlooked; nor did it mean that his family's views were being completely ignored. (The NHS Trust did, for

example, get a second SALT opinion regarding Mr J's diet, and changed Mr J's consultant at the family's request.) But it did mean that important opportunities to ensure that all relevant information necessary to achieve the best possible outcome for Mr J were lost. We have accordingly concluded that communication with Mr J's family in this respect was inadequate and must be regarded as a significant service failure.

The Council

- ⁹⁶ The Stage 2 investigation into Mr K's complaint to the Council, particularly about the support and communication provided prior to Mr J's admission, was protracted. We note that the Council accepted that there had been a number of shortcomings in the service which had been provided. It is clear, for example, that the Coquet Trust had been asking for some time for funding for additional support hours in the period before Mr J's admission. This is understandable in terms of the deterioration which was clearly taking place, given the changes in his physical and physiological condition due to the onset of dementia and epilepsy. The question of how much extra support and funding should have been provided is not a matter for us. However, the Stage 2 investigation confirmed that, given that Mr J's deterioration was so severe as to require assessment in hospital, not only was it clear that those requests were not considered with appropriate urgency, it could also be argued that it should have been evident that the basis for funding needed to be radically revised. These matters have been dealt with at length in the earlier stages of the Council's complaints process. Nevertheless, despite the significance of those failings, we do not think it is possible to conclude that Mr J's increasing depression
- and dependence on others can be linked directly to a failure to provide appropriate day time and general support over a fairly long period before his admission to the NHS Trust. There can be little doubt, however, that the delay in funding sufficient support must have impacted on Mr J's quality of life in that period to some degree, as the Coquet Trust's records show that they were spending increasing amounts of time supporting Mr J with basic tasks, such as feeding and dressing, which meant that there was less time available for them to do anything else, such as to take him out, or to support him in other activities.
- ⁹⁷ During the period when Mr J was in hospital, the main responsibility for providing sufficient day-time activity therapy would have rested primarily with the NHS Trust, and not with social services. That is understandable. But the social services' decision to reduce the support hours available to him to only eight per week during that period had a significant impact on the amount of contact Mr J could have with his wife, Mrs N. It would appear that that was insufficient time to support her to make more than one visit a week, because of the distance of the hospital from their home. Despite the positive impact his wife's visits were recorded as having on him, no consideration seems to have been given to increasing those hours to allow more frequent contact between them. That omission demonstrated a disappointing and unacceptable disregard for Mr J's relationship with his wife and his well-being.
- ⁹⁸ It is possible that that omission could have in part resulted from the lack of adequate communication during important periods, between social services' staff and the Coquet Trust's staff with Mr J's family, which the Stage 2 investigation revealed. In fact, social services' contact with his family after Mr J's

admission seems to have been very limited. Further, there was not even a social services representative at the first of the CPA meetings (Annex B, paragraph 29) on 1 December 2006. We appreciate that Mr J's then social worker was sick, but that did not mean that there was not a continuing duty on social services to provide the necessary input into his care planning and provision in order to promote Mr J's best interests whilst he was in the hospital. They clearly failed to do that.

99 That failing was all the more marked, however, once Mr J had been assessed as ready for discharge in January 2006. It is quite clear from the OT's detailed assessment of Mr J and Mrs N's home in January 2006 (paragraph 35) that it would have been inappropriate to suggest that Mr J should return to his former accommodation. Whilst we recognise that Mr J's family do not agree with that view, given the high risk of Mr J falling there, we do not consider that that was an option realistically open to the Council. In fact the need for rehousing had first been identified by social services in October 2005 (paragraph 29), and reinforced by Dr A in November 2005. However, that then placed the onus squarely on the Council to find appropriate ground floor accommodation for Mr J and his wife as soon as possible. Yet, as we have shown, that never happened. Instead, Mr J spent the next five months waiting in the hospital, and was then discharged into unsuitable, first floor accommodation, where he had to be locked in to prevent him from falling in the lift or on the stairs, and from wandering, and where he was still living when he died ten months later. All of that was simply unacceptable.

100 During all of that time, not only was no sense of urgency brought to bear on the accommodation issue by the Council, but

a situation developed which could at best be described as unfortunate, but which was, in reality, both astonishing and absurd. This arose from the fact that the Council took no action to resolve the housing issue, other than to expect Mr J to use the same choice-based bidding system as anyone else. Under that system (Annex B, paragraph 37) Mr J, or someone he had nominated to act on his behalf, was required to bid for advertised properties. This was entirely inappropriate in Mr J's circumstances and effectively meant that social services had abandoned their clear duty to seek actively to resolve Mr J's urgent housing need (Annex B, paragraph 24). To add insult to that injury, there is no evidence to show that any efforts were made to ensure that this process was ever properly explained to, or understood by, Mr J and his wife. Nor do the records show that he was invited to nominate someone else to act on his behalf in this matter, or that the process was explained to Mr K or anyone else in Mr J's family; nor indeed that any of the care professionals working with Mr J had taken on this role. As a direct result, Mr J's medical priority was first removed in July 2006 because he had not made any bids, and then reinstated a month later, when the Coquet Trust explained to the housing agents that Mr J had been in hospital. Then two offers were made and refused without any discussion with Mr J or his family, and even, in the second instance, apparently without the involvement of Mr J's social worker. Further, the second property was refused on the grounds that it would take 'too long' to make the required adjustments, without any attempt to establish exactly how long it would take, or indication whether another property was likely to become available in that period. The housing agency then ceased to make any further offers apparently because of the lack of interest shown in the first two.

¹⁰¹ We note that the Council, in their response to us, have suggested that the difficulties arose because Mr J had not nominated a specific individual to bid for him (paragraph 72) and had shown no interest in any of the potentially suitable properties that were coming up at that time (paragraph 73). The Council also imply (paragraph 74), that it was not surprising that the housing agency made no further offers, as the properties that had been declined had '*met the basic requirements*'.

¹⁰² We find that response outrageous and indefensible. It entirely ignores the question of Mr J's capacity to act on his own behalf and the fact that the process was totally inappropriate for him and his circumstances. It pays no heed to the legal duty on social services to seek the help of the housing and health authorities to resolve the problem, and failing that, to seek to resolve it themselves. It also disregards the fact that Mr J and his family were unaware of the process in place, and that the properties were turned down by social services and the Coquet Trust, and not by Mr J or a nominated representative, as being unsuitable for Mr J's needs. There is little sign here of social services and the housing agency working in partnership to meet Mr J's urgent accommodation needs, as the Council say was the case (paragraph 71). Indeed, it seems highly unlikely, in the light of these developments, that had Mr J lived, he and his wife would ever have moved from the unsuitable locked accommodation in the care home.

¹⁰³ These events are all the more alarming when considered against the background of the national strategy and guidance in place intended to improve the lives of those with learning disabilities, giving them greater choice and control over their lives, and the guidance issued following the Bournemouth case,

intended to ensure that individual's human rights were given proper consideration. We find that the Council's failure to review regularly and record why Mr J was being effectively detained in unsuitable, locked accommodation, and their failure to take appropriate and urgent action to find suitable permanent accommodation, were so serious as to amount to service failure.

¹⁰⁴ That same guidance highlighted the importance of involving the family in care planning for service users. The failure to involve Mr J's family sufficiently in trying to resolve the accommodation issue was particularly serious. Although staying with Mr K might have not been a viable option for Mr J in the long term, Mr K must have viewed, with distress, the fact that this was never discussed with him nor tried as an emergency interim measure, and that he was not given the opportunity to help in the search for appropriate accommodation, which might have led to Mr J being able to spend the last months of his life in relative freedom (although we recognise that he was no longer able to go out independently) and in more congenial surroundings.

¹⁰⁵ We turn finally to the investigation of Mr K's complaint to the Council. This took far longer than it should have to complete (15 months, rather than the 28 days set out in the regulations – Annex B, paragraph 40), and we agree with the Stage 3 panel that Mr K should have been offered an interview. In the main, however, the investigation had been thorough in acknowledging and responding appropriately to many points of detail in the complaint. There was, nevertheless, a key omission, which was the overwhelming failure to recognise that in failing to follow the relevant guidance, and in failing to take timely and appropriate action to find permanent suitable accommodation for Mr J and his wife, the Council were not

just failing to act in Mr J's best interests, but failing to ensure that Mr J's human rights were adequately safeguarded.

The Coquet Trust

¹⁰⁶ Mr K complained about the amount and content of the practical day-to-day support provided to Mr J by the Coquet Trust. However, the Coquet Trust were not responsible for planning the care or care management arrangements on behalf of social services: their contract with the Council was specifically for the provision of a certain number of hours of support to assist Mr J and his wife with basic daily living tasks. We have seen that the care provided by the Coquet Trust was considered at all stages of the social services complaints procedure; and the investigation of the issues complained about was generally thorough and the findings reasonable. We have had no reason to repeat those investigations. Mr K has made a number of criticisms of the practical arrangements but it seems to us that Coquet Trust staff did what was reasonably possible within the time allocated to them. We note, for example, that the funding available to maintain contact between Mr J and his wife while he was in hospital was determined by social services, and was insufficient for the contact to be anything other than minimal. After Mr J's discharge, they were, of course, providing Mr J with 24-hour, live-in support.

¹⁰⁷ Further, although we found that the Coquet Trust's records were sometimes sparse and seemingly incomplete, there was nothing in the available evidence to suggest that Mr J was provided with an unacceptable standard of care in the period before his death. In particular, we do not conclude that Coquet Trust staff failed to observe signs of imminent serious illness –

especially as we note that the Coquet Trust asked both the community nurse and his GP to see Mr J three days before his final admission to hospital, and neither the nurse nor GP raised any urgent concerns about Mr J's health.

¹⁰⁸ We turn finally to the complaint that the Coquet Trust staff were a part of the wider failure to communicate adequately with Mr J's family. We consider that prior to Mr J's admission, the responsibility for keeping Mr J's family properly updated rested primarily with Mr J's social worker (although we note that that would have required the Coquet Trust staff to have kept him informed, which was identified as a failing on their part in earlier stages of the complaints process). We also note that the Coquet Trust staff did not inform Mr K when Mr J's imminent admission to hospital was being considered in November 2005, although they did call him that evening to tell him of Mr J's admission. We do not, however, find that the support workers failed to facilitate Mr J's contact with his family following his discharge. The records clearly show that it was part of the support workers' recognised duties to call Mr J's family each day to update them on Mr J's health and activities in the previous 24 hours and to support Mr J in speaking to his family, and that this was to be done when Mr J was safe and did not need their support in other ways; and that was what happened. We appreciate that Mr J's family would have preferred there to be a landline in Mr J and Mrs N's flat in the care home, in order to be able to contact Mr J when they wished. However, that accommodation was meant to be temporary only, and given the daily contact call, we do not see it as a failing on the part of the Coquet Trust staff that they did not press for a landline to be installed in line with the family's wishes.

Injustice

¹⁰⁹ So what was the injustice caused to Mr J by the service failings we have identified above? As we have already indicated, we cannot agree with Mr K that it is possible to conclude that, had all the health and social care staff involved in Mr J's case carried out their duties in line with the relevant guidance and best practice the outcome for Mr J would have been dramatically different, in the sense that his condition would not have worsened as it did and he would not have died. Mr J's condition was clearly fluctuating, but it was recognised by a wide range of professional staff involved with Mr J's care that he had been slowly deteriorating over a long period, and that that deterioration became more rapid with the onset of dementia and epilepsy. Accordingly, even if Mr J had been provided with more support sooner, and suitable accommodation had been found much earlier, there is little possibility that he would have been able to regain his former skills and health, or retain those that he had before entering hospital for much longer. We certainly cannot conclude that he would not have died when he did.

¹¹⁰ It is also not possible for us to determine, with any level of certainty, what level of additional distress was caused to Mr J by his unnecessarily prolonged stay in hospital, and in accommodation that was unsuited to his needs. We accept, however, that this will have been significant, particularly for the period when Mr J was in hospital and he was clearly missing his wife.

¹¹¹ What we can, however, say with certainty is that those service failings meant that opportunities were not taken to assess Mr J's needs promptly and appropriately, with due regard to his rights, best interests and wishes, and his relationship

with his wife and family. We cannot know precisely what difference that might have made, but it seems highly likely to us that it would have had some impact on the quality of his life, and hence his well-being, in the last 18 months or so of his life. That injustice cannot now be put right.

¹¹² Those service failings also, however, had a negative impact on Mr J's family in that, had they been properly involved in Mr J's care planning, they might have been able to represent Mr J's interests more successfully. They might, for example, have been able to put forward other options to meet Mr J's accommodation needs, at least on an interim basis, or been able to secure more urgent action by the Council, so that Mr J could spend his last months in more congenial surroundings with easier and more regular contact with his family. The overwhelming injustice to them is that they were wrongly denied those opportunities to contribute to Mr J's care planning, and will never now know if they could have made a difference to the quality of Mr J's life in those last months. We have no doubt that that uncertainty is a cause of significant and ongoing distress to Mr K and the rest of Mr J's family.

Recommendations

¹¹³ The NHS Trust and the Council have both previously offered their apologies for the shortcomings identified during previous stages of the complaints system, and taken various steps (as set out in their responses in Annex F) to try and prevent a recurrence. We do not, however, consider that those provide sufficient remedy for the injustice arising from the very serious failings identified in this report. We therefore make the following recommendations that the NHS Trust and the Council should:

- provide Mr K with a full acknowledgement of the serious service failures identified in this report, together with an apology for the distress those failings caused Mr J's family; and
- pay Mr K (as the family's representative) a sum of £2,000 in recognition of the distress caused to Mr J's family by the failings identified in this report; (with the NHS Trust and the Council contributing an equal share to that sum – namely £1,000 each). Mr K has informed us that he will be donating all of the money to charity.

114 Whilst we recognise that there have been changes in the legislative framework since the events in this case which, if fully complied with, should mean that the failings described in this report should not be repeated, we do not see the existence of that framework as sufficient reassurance in itself that appropriate lessons have been learnt. We therefore additionally recommend that, within three months of the issue of the final report, the NHS Trust and the Council each:

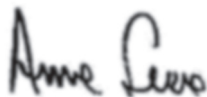
- prepare an action plan which describes what they have done (or will do) to ensure that they have learnt from the failings identified in this report and which describes what they intend to do, including timescales where appropriate, to avoid a recurrence of those failings;
- send a copy of the action plan to the Ombudsmen and Mr K. The NHS Trust should also share its action plan with NHS North East (the strategic health authority), Monitor, Newcastle Primary Care Trust (the commissioning body) and the Care Quality Commission; and

- ensure Mr K is regularly updated on progress against the action plan. The NHS Trust should also ensure that NHS North East, Monitor, Newcastle PCT and the Care Quality Commission are updated.
- 115 The NHS Trust and the Council have agreed to these recommendations.

Conclusion

116 We found significant failings on the part of both the NHS Trust and the Council which meant that they were unable to demonstrate that Mr J's basic human rights (to liberty and to family life) had been given appropriate consideration when decisions were being made as to his care needs. As a result, important opportunities were missed to try to ensure that Mr J got the best out of his everyday life in the last 18 months of his life in particular, and significant and ongoing distress was thereby caused to Mr K and the rest of Mr J's family. We are aware from Mr K's comments on a draft of this report that, contrary to our findings, he remains convinced that Mr J's clinical diagnosis was wrong and that the care and treatment that Mr J received was accordingly not only misconceived, but in fact hastened his decline and death, and that this misdiagnosis was the result of discrimination against Mr J. We have considered all of Mr K's representations very carefully, but on the basis of the evidence we have seen, and the professional advice we have received, we cannot agree with him. Accordingly, we find the NHS Trust and the Council's agreements to our recommendations to be a suitable outcome to this partly justified complaint.

117 Although we have been unable to reach the conclusions that Mr K was seeking, we hope that this report will provide him and the rest of Mr J's family with at least some of the explanations they were seeking, and will draw to a close what had been a long and complex complaints process for all those involved.



Ann Abraham
Health Service Ombudsman

Anne Seex
Local Government Ombudsman

November 2011

Annex A – The determination of complaints by the Health Service Ombudsman and the Local Government Ombudsman

Remits and powers

The Health Service Ombudsman's remit

- 1 By virtue of the *Health Service Commissioners Act 1993*, the Health Service Ombudsman is empowered to investigate complaints against the NHS in England. In doing so she considers whether a complainant has suffered injustice or hardship in consequence of a failure in a service provided by bodies such as the NHS Trust, a failure to provide a service it was empowered to provide, or maladministration in respect of any other action by, or on behalf of, the NHS Trust.
- 2 She may carry out an investigation in any manner which, to her, seems appropriate in the circumstances of the case and may make such enquiries and obtain information from such persons as she thinks fit. If the Ombudsman finds that service failure or maladministration has resulted in an injustice, she will uphold the complaint. If the resulting injustice is unremedied, in line with her Principles for Remedy¹ (Annex B, paragraphs 7 and 8), she may recommend redress to remedy any injustice she has found.

The Health Service Ombudsman – premature complaints

- 3 Section 4(5) of the *Health Service Commissioners Act 1993* states that the Health Service Ombudsman may not generally investigate a complaint until the NHS complaints process has been exhausted, and this is the approach taken by the Health Service Ombudsman in the majority of NHS complaints made to her. If, in the particular circumstances

of any case, the Health Service Ombudsman considers that it is not reasonable to expect the complainant to have followed the NHS route, she may accept the case for investigation notwithstanding that the complaint has not been dealt with under the NHS complaints process. This is a matter for the Health Service Ombudsman's discretion after proper consideration of the facts.

- 4 In this instance, Mr K's complaint was directly referred by the Healthcare Commission (which at the time oversaw the second stage of the NHS complaints procedure) to the Health Service Ombudsman for consideration because Mr K had also complained to the Local Government Ombudsman about the service provided by the Council.

The Local Government Ombudsman's remit

- 5 Under Part III of the *Local Government Act 1974*, the Local Government Ombudsman has wide discretion to investigate complaints of injustice arising from maladministration by local authorities (councils) and certain other public bodies. She may investigate complaints about most council matters, including social services and the provision of social care.
- 6 If the Local Government Ombudsman finds that maladministration has resulted in an unremedied injustice, she may recommend redress to remedy any injustice she has found.

Powers to investigate and report jointly

- 7 *The Regulatory Reform (Collaboration etc between Ombudsmen) Order 2007* clarified the powers of the Health Service Ombudsman

¹ Principles for Remedy is available on www.ombudsman.org.uk.

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.

- 8 In this case, the Ombudsmen agreed to work together because the health and social care issues were so closely linked. A co-ordinated response consisting of a joint investigation leading to the production of a joint conclusion and proposed remedy in one report seemed the most appropriate way forward.

Annex B – The basis for the Ombudsmen’s determination of complaints

Introduction

- 1 In simple terms, when determining complaints that injustice or hardship has been sustained in consequence of service failure and/or maladministration, we generally begin by comparing what actually happened with what should have happened.
- 2 So, in addition to establishing the facts that are relevant to the complaint, we also need a clear understanding of the standards, both of general application and those which are specific to the circumstances of the case, which applied at the time the events complained about occurred, and which governed the exercise of the administrative and clinical functions of those bodies and individuals whose actions are the subject of the complaint. We call this establishing the overall standard.
- 3 The overall standard accordingly has two components: the general standard, which is derived from general principles of good administration and, where applicable, of public law; and the specific standards which are derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.
- 4 Having established the overall standard, we then assess the facts in accordance with the standard. Specifically, we assess whether or not an act or omission on the part of the body or individual complained about constitutes a departure from the applicable standard.
- 5 If so, we then assess whether, in all the circumstances, that act or omission falls so far short of the applicable standard as to constitute service failure or maladministration.

- 6 The overall standard we have applied to this investigation is set out below.

The general standard

Ombudsman’s Principles

- 7 In February 2009 the Health Service Ombudsman republished her *Principles of Good Administration, Principles of Good Complaint Handling* and *Principles for Remedy*.¹ These are broad statements of what she considers public bodies should do to deliver good administration and customer service, and how to respond when things go wrong.
- 8 The same six key Principles apply to each of the three documents. These six Principles are:
 - Getting it right
 - Being customer focused
 - Being open and accountable
 - Acting fairly and proportionately
 - Putting things right, and
 - Seeking continuous improvement.
- 9 We have taken all of these Principles into account in our consideration of Mr K’s complaint.

Disability rights considerations

- 10 At the time relevant to this complaint, public bodies (and some other bodies with public functions) and service providers had to comply with the *Disability Discrimination Act 1995* and the *Disability Discrimination Act 2005*, including the duty to make reasonable adjustments. (From 1 October 2010 the

¹ The *Ombudsman’s Principles* is available at www.ombudsman.org.uk.

Equality Act 2010 replaced most of the disability discrimination acts.) They also had to have regard to the various statutory codes of practice that had been published to assist in the interpretation of the legislation.

- 11 Under the *Disability Discrimination Act 2005*, public bodies had a general duty to eliminate discrimination and harassment, to promote equality of opportunity and positive attitudes, to encourage participation in public life, and to take steps to take account of disabled persons' disabilities, even where that involved treating disabled persons more favourably than other persons.
- 12 It is not the role of the Ombudsmen to adjudicate on matters of disability discrimination law or to determine whether the law has been breached: that is a matter for the courts. The Health Service Ombudsman's Principles of Good Administration do, however, state that the Principle of '*Getting it right*' includes acting in accordance with the law and with regard for the rights of those concerned, and taking reasonable decisions based on all relevant considerations.
- 13 If it appears that someone's disability rights are engaged in relation to the events complained about, they will expect the public body, in accordance with the Principles of Good Administration, to have had regard to those rights in the way it has carried out its functions, and to have taken account of those rights as a relevant consideration in its decision making.
- 14 If the public body is unable to demonstrate that it has done so, the Ombudsmen will take that fact into account when considering whether there has been maladministration and/or service failure.

- 15 In cases where the Ombudsmen identify maladministration and/or service failure, it does not necessarily follow that they will also find that injustice has been caused as a result.

Human rights considerations

- 16 The *Human Rights Act 1998*, which came into force in England in October 2000, requires public authorities to act in a way that is compatible with the *European Convention on Human Rights*. Of particular relevance to Mr K's complaint are the following rights contained in the *European Convention on Human Rights*:
 - Article 5 – right to liberty,
 - Article 8 – right to respect for private and family life,
 - Article 14 – prohibition of discrimination.
- 17 Public bodies (and some other bodies with public functions) must comply with the *Human Rights Act 1998*. Underpinning human rights law are the key principles of fairness, respect, equality, dignity and autonomy.
- 18 It is not the role of the Ombudsmen to adjudicate on matters of human rights law or to determine whether the law has been breached: those are matters for the courts. The Health Service Ombudsman's Principles of Good Administration do, however, state that the Principle of '*Getting it right*' includes acting in accordance with the law and with regard for the rights of those concerned, and taking reasonable decisions based on all relevant considerations.
- 19 If it appears that someone's human rights are engaged in relation to the events complained about, they will expect the public body, in accordance with the Health

Service Ombudsman's Principles of Good Administration, to have had regard to those rights in the way it has carried out its functions, and to have taken account of those rights as a relevant consideration in its decision making.

- 20 If the public body is unable to demonstrate that it has had regard for, and taken account of, human rights, the Ombudsmen will take that fact into account when considering whether there has been maladministration and/or service failure.
- 21 In cases where the Ombudsmen identify maladministration and/or service failure, it does not necessarily follow that they will also find that injustice has been caused as a result.

The specific standards

Health and social care: relevant legislation, guidance, policy and professional standards

- 22 The main purpose of the *Mental Health Act 1983* (MHA – subsequently amended by the *Mental Health Act 2007*) is to allow compulsory action to be taken, where necessary, to make sure that people with mental disorders get the care and treatment they need for their own health or safety, or for the protection of other people. It sets out the criteria that must be met before compulsory measures can be taken, along with protections and safeguards for patients. Part 2 of the MHA sets out the civil procedures under which people can be detained in hospital for assessment or treatment of mental disorder. Detention under these procedures normally requires a formal application by either an approved mental

health professional or the patient's nearest relative, as described in the Act. An application is founded on two medical recommendations made by two qualified medical practitioners, one of whom must be approved for the purpose under the Act. Different procedures apply in the case of emergencies.

- 23 The *Chronically Sick and Disabled Persons Act 1970* places a duty on local authorities to:
- inform itself of the need for making arrangements for disabled persons within its area;²
 - arrange practical assistance in the home and provide any adaptations or additional facilities designed to secure greater safety, comfort or convenience by directly providing equipment, adaptations, loans or grants.³
- 24 The *National Health Service and Community Care Act 1990* clarified that local authorities had a duty to assess the individual community care needs of any person who, in their view, required services, to decide what services should be provided, and to notify and invite assistance from health or housing bodies where appropriate.⁴ The duty, however, remains on the social services authority to meet the assessed needs of a disabled person, even if that need is a housing need. A social services authority can, therefore, invite a housing authority to assist it to meet a housing need, but if such assistance is not forthcoming the social services authority must act.
- 25 *Moving into the Mainstream: The Report of a National Inspection of Services for Adults with Learning Disabilities*, a report by the

² *Chronically Sick and Disabled Persons Act 1970*, section 1.

³ *Chronically Sick and Disabled Persons Act 1970*, section 2 (1)(e).

⁴ *National Health Service and Community Care Act 1990*, section 47(1) and (3).

Department of Health (DH), was issued to local authorities in 1998 and set out best practice guidance about the planning and provision of services for people with learning disabilities. This included the following:

- Standard 1: *'Responsive services'* stated: *'the local authority arranges and provides, in partnership with other organisations, services which are responsive to the assessed needs of adults with learning disabilities'*.
- Criteria 5 and 6, under Standard 1, stated: *'People with learning disabilities [should] have personally planned programmes of day activities [and] ... undertake employment and other meaningful activities.'*

The criteria under Standard 2 (*'Assessment, care planning and case management'*) included *'As a result of their involvement in the care planning process service users and carers receive the services they need and prefer. ...'* Under Standard 3: *'Information, communication and consultation'*, Criteria 3 stated: *'the social services Directorate consults with users and carers ... [about] individual and service planning.'*

- 26 In *Valuing People: A New Strategy for Learning Disability for the 21st Century: a White Paper* (2001) the DH outlined the future strategy and objectives for improving the lives of people with learning disabilities. It identified four key principles: legal and civil rights (including rights to education, to vote, to have a family and to express opinions); independence; choice; and inclusion.
- 27 Objective 6 of the White Paper was: *'To enable people with learning disabilities and their families to have greater choice and control over where and how they live'*.

28 Another of the targets set by the White Paper was: *'All people with a learning disability to have a Health Action Plan by June 2005'*. The intention was that these Plans would provide an overview of actions needed to keep a person healthy, linking them with a full range of services and support. (*Action for Health – Health Action Plans and Health Facilitation – Detailed Good Practice Guidance on Implementation for Learning Disability Partnership*, DH, 2002.)

29 The Care Programme Approach (CPA) was introduced in 1991 after the publication of *HC (90) 23/LASSL (90) 11* by the Department of Health. It provided a framework for effective mental health care. It was updated by a further publication by the Department of Health *Effective care co-ordination in mental health services: modernising the care programme approach* in 1999. Its four main elements are:

- a. Systematic assessment of the health and social needs of people accepted into specialist mental health services.
- b. A care plan identifying health and social care from a variety of providers.
- c. The appointment of a key worker to monitor and co-ordinate care.
- d. Regular review.

30 In a policy statement, *Making decisions on behalf of mentally incapacitated adults* the Lord Chancellor's Office, in 1999, set out proposals to reform the law relating to the provision of care and treatment to people who lacked the capacity to consent. (This, in turn, led to the passing of the *Mental Capacity Act 2005*, the provisions of which have since been phased in.)

31 To accompany *Health Service Circular 2001/023, Good Practice in Consent: achieving the NHS plan commitment to*

patient-centred consent practice, the DH produced an implementation guide containing blank pro formas to be used by clinicians ‘*where it would be usual to seek written consent but an adult patient ... lacks capacity to give or withhold consent to treatment*’. The implementation guide states, at paragraph 6, that:

‘Where an adult does not have the capacity ... this fact should be documented [on the pro forma] along with the assessment of the patient’s capacity, why the health professional believes the treatment to be in the best interests, and the involvement of people close to the patient. ...’

- 32 The DH issued interim guidance in December 2004 following what became known as the Bournemouth case, which involved a man with autism and a learning disability who the European Court of Human Rights ruled had been deprived of his liberty. The European Court said that the question of whether someone had been deprived of their liberty depended on individual circumstances. The man in question had not had the capacity to consent to his admission to hospital. The fact that the man had not attempted to leave the hospital, or that had he tried to he would have been detained in his own best interests, did not of itself mean that the man was not being ‘detained’ by the hospital. The European Court said that the distinction between deprivation and restriction of liberty was ‘*one of degree or intensity and not one of nature or substance*’. The Court went on to rule that the absence of procedural safeguards surrounding admission at Bournemouth Community and Mental Health NHS Trust had failed to protect the patient against arbitrary deprivation of liberty on grounds of necessity, and therefore failed to comply with Article 5 of the *European*

Convention on Human Rights. The European Court was also concerned that staff might be able to assume:

‘full control of the liberty and treatment of a vulnerable incapacitated individual solely on the basis of their own clinical assessments completed as and when they saw fit.’

- 33 The DH advised health and local authorities that the effect of the judgment was that it would be unlawful (without the authorisation of the High Court) to provide care or treatment for an incapacitated patient in a way that amounted to deprivation of liberty unless the patient were detained under the MHA. Given that the NHS and local authorities would still need to care for incapacitated patients whose safety and quality of care should not be compromised, they would need to consider interim action to protect against the risk of arbitrary deprivation of liberty:

‘[Bodies] will want to ensure they have systems in place so that when making arrangements to provide care to an incapacitated person which involves a restriction on the liberty of that person consideration is given to whether what they are proposing amounts in practice to a deprivation of that person’s liberty ... The same question will need to be asked when reviewing the circumstances of those people who they have already placed ...’

- 34 The DH gave examples of relevant good practice for NHS bodies and local authorities:
- taking decisions in a structured way;
 - documented care planning, involving family, friends and carers;
 - considering alternatives to admission to hospital or residential care;

- providing appropriate information to patient, family, friends and carers;
- helping patients retain contact with family, friends, and carers; and
- ensuring that assessment of capacity and care plans were kept under review.

³⁵ Chapter 2.3 of *Assessment of Mental Capacity: Guidance for Doctors and Lawyers* – produced jointly by the British Medical Association and the Law Society – second edition 2004, stated:

‘Where there are doubts about capacity, it is important that people are assessed when they are at their highest level of functioning because this is the only realistic way of determining what they may or may not be capable of doing.’

³⁶ The Supporting People programme, an initiative of the Department of Communities and Local Government, launched on 1 April 2003, aimed to enable vulnerable people to live more independently and maintain tenancies by providing support to prevent hospitalisation, institutional care or homelessness. This programme was delivered locally by 150 administering authorities and more than 6,000 providers:

‘A working partnership of local government, probation, health, voluntary sector organisations, housing associations, support agencies and service users’ [to] ‘encourage collaborative working between stakeholders of the programme ... Partnership is paramount.’

Your Choice Homes

³⁷ For the period of the events in this complaint the Council had entered into a partnership with local housing associations and introduced

a choice-based bidding scheme called Your Choice Homes. Within the terms of the scheme, registered applicants could bid for up to three advertised properties a week. Urgent needs for re-housing were given priority. The terms of Your Choice Homes, *‘Information for Applicants’*, included: *‘A customer can also nominate someone to bid on their behalf.’*

The Coquet Trust’s role

³⁸ The Coquet Trust’s contract with social services⁵ stated that *‘the object of the agreement is to provide housing support’* for Mr J and his wife. The list of support tasks included: advice on food preparation or storage, shopping, social events and good neighbour tasks. It did not include care planning and review.

³⁹ The Coquet Trust’s own mission statement included:

- (i) *‘To offer ... choice, rights and ... independence for service users.’*
- (ii) *‘To work in partnership with social services, care agencies and housing provider to ensure quality standards are continuously achieved and improved upon.’*

Complaint handling

The Council’s complaint handling

⁴⁰ Social services authorities have a duty to provide a complaints procedure and the statutory complaints process applicable to this complaint was that contained within *The Complaints Procedure Directions 1990* (the 1990 Directions – since superseded by 2006 Regulations).

⁵ The contract is dated 24 February 2003.

41 The 1990 Directions established a three-part process: a first (informal) stage; a formal second stage if the complainant remained dissatisfied – the matter being considered at Stage 2 by a designated complaints officer, and an investigator might be appointed. At Stage 3, the complainant had the right to request an independent panel review of the Stage 2 investigation. Stage 1 is essentially an opportunity for the local authority to attempt problem solving and conciliation and there is no statutory timescale for its completion. It is, however, possible to go straight to Stage 2 if either the complainant so wishes or the local authority considers it appropriate. At Stage 2, the local authority must respond to the complaint within 28 days or alternatively explain why this is not possible – and then, in any case, respond within three months. If the complainant is not satisfied, and he or she writes to that effect within 28 days, then the local authority has to appoint a review panel, which must meet within 28 days, and then within 24 hours issue its written recommendations to the relevant parties to the complaint. The local authority must then decide what to do, and write telling those parties within 28 days.

NHS complaint handling

- 42 *The NHS (Complaints) Regulations 2004* created the procedure applicable to Mr K's complaint, with provision for handling at local level by NHS bodies; if the complainant was dissatisfied, the complaint was given further consideration by the Healthcare Commission. If the complainant remained dissatisfied, then the matter could be referred to the Ombudsman for consideration.
- 43 In certain circumstances, if the Healthcare Commission took the view that it would be more appropriate for a complaint referred to them to be considered by the Health Service Ombudsman, then they could refer the matter direct to the Ombudsman without any further involvement on their part.

Annex C – Mr K’s recollections and comments

Taken from Mr K’s correspondence and from notes of a meeting held with Mr K and his wife (Mrs M), his sister (Mrs L) and family on 26 November 2008

Introduction

- 1 Mr K had initially instigated his complaint with a view to getting Mr J out of hospital and back into his own home, or to other permanent accommodation. Temporary accommodation had clearly been inappropriate, particularly the care home. Due to Mr J’s sad death, this had not been achieved. Clearly, the outcome the family now sought was different. Mr K explained that the family considered that Mr J’s human rights had been ignored, as had their human rights as a family to be included in, and treated fairly in respect of, the decisions that had been made about what was considered best for Mr J. Mr K said that the family had been in almost daily contact with Mr J and had spent a lot of time either visiting him, or having him and his wife to stay with them. Mr J’s carers had been well aware of the extent of the family’s contact; nevertheless, the family had not been consulted prior to Mr J’s admission, or asked to provide information about Mr J which would have been relevant to assessments of his condition. Mr K believed that Mr J had been discriminated against because he had Down’s syndrome. Mr K noted that Mr J had not suffered from any of the usual congenital problems associated with Down’s syndrome and had rarely been ill. He said that he did not believe that Mr J’s sudden decline had been due to early onset dementia, but had resulted from:
 - assumptions made that the symptoms Mr J had been displaying had been caused by dementia, which meant that other possible causes of his decline had not been properly considered. Mr K believed that the symptoms Mr J displayed prior to admission had been caused by depression resulting from his mother’s death and the loss of a friendship. He also believed that during this period, prior to his admission, Mr J had not been provided with sufficient activities and support to maintain his skills and abilities or to provide him with a proper diet.
 - The admission to hospital and the decision to keep him there, although he had not been sectioned under the MHA, which had exacerbated his decline. Mr K pointed out that the side effects of the medication¹ Mr J had been prescribed had resulted in his being heavily sedated, and had therefore considerably reduced his alertness and abilities. Mr J had not been provided with sufficient activities to help counter this; for example, he had not been allowed to use stairs or provided with other exercise, and had therefore lost mobility skills. His physical skills had been further reduced by the decision to place him on a soft diet. Mr K said that Mr J had been treated as an invalid and had not been allowed to function to his full capacity, with health and safety reasons often given as an excuse.
 - Mr J being traumatised and distressed by the admission to hospital and being kept there, and by his stay at the care home.
 - The temporary accommodation provided at the care home being unsuitable, which had further exacerbated Mr J’s loss of skills and abilities.

¹ Lexapro – an antidepressant with side effects which can include extreme tiredness and dizziness.

- 2 Mr K said that social services had failed to question what was happening to Mr J, and healthcare clinicians had not been interested in his character. Mr K believed that, had Mr J received appropriate support and care, he would still be alive. Mr K hoped that the investigation would result in these failings being acknowledged and apologised for, and that those responsible for not providing Mr J with an appropriate service, and for depriving him and his family of their human rights, would be made fully accountable for any identified failings. He also hoped that the investigation would prevent others not having to endure a similar experience.

Mr J prior to admission

- 3 Mr K gave a detailed description of Mr J's personality, general condition and skills, including in particular the week before he was admitted. He said that Mr J had been active and outgoing, and had enjoyed excellent health and had not been on medication prior to November 2005. Mr K explained that in many ways Mr J had been highly intelligent, but that due to his condition, there had been limits to his comprehension and ability to understand the implications of what was being said.
- 4 Mr J had also had a large tongue, which meant that he had had difficulty speaking and communicating orally; consequently people had often assumed that his comprehension was less than it actually was, however he had understood many things. Mr J had had a strong wish to be as independent as possible. The family had supported this, but had still wished to remain in the background as a safety net, given that both Mr J and his wife had learning disabilities. Mr K gave an example of an incident in which he had shadowed Mr J during a shopping activity and had been spotted by Mr J. Mr J had made it clear that he had understood that his brother had been shadowing him and was offended by this. Mr K told us that Mr J would have found it difficult to have conversations with a stranger of the kind it was suggested he had had. The family therefore felt that the notes in the records which said that Mr J had made various statements could not have been an accurate reflection of what had actually been said by him. Mrs L pointed out that over the years Mr J had never been provided with a speech therapist, although he had clearly needed one.
- 5 Mr K said that Mr J had been polite. If he had felt pressurised, nervous or uncomfortable he would fiddle with his cuffs, cough and indulge in other forms of behaviour which the psychologist had described as ritualistic, or an indication of compulsive behaviour. However, Mr J had always displayed such behaviours since childhood, and they had therefore been an integral part of his personality, and not evidence of a cognitive decline, as the psychologist had suggested. The cognitive functioning tests that Mr J had been subjected to would have caused him considerable distress, and he would not have been able to function normally during these. Mr K pointed out that the records said that on one occasion when the testing had stopped and Mr J had been asked if he would like a cup of tea and a biscuit, it had been noted that he had '*perked up*' and behaved very differently. Mr K, therefore, questioned the accuracy of the psychologists' assessments of Mr J when the reports contained statements that were clearly inaccurate, recording Mr J as doing things which he could not do, and describing his usual behaviour as evidence of a cognitive decline. He believed that Mr J had been labelled with dementia.

- 6 Mr J had been kind, had wished to please people and had been very sociable; when his wife, Mrs N, had been *'in a mood'*, Mr J would be the one who could and would get her out of it. Mrs N had been sensitive to voice intonation and to the way that a question had been phrased, and she would try to give the answer that she thought the questioner wanted to hear. This made asking her about Mr J's behaviour completely unreliable.
- 7 Mr J's personality had been quite different from his wife's. Mr J needed activities to maintain his skills, and he had been more active and outgoing and had liked to do things such as going to the pub, playing snooker and that he had loved *'office work'*. Mrs L said that she had taught Mr J some reading skills. Mr K said that until 2003 Mr J had had a placement in an office in which he had done the photocopying. He had loved this activity and it had given him great self-esteem. The placement had been for a limited time and when it came to an end it had been extended, but could not be made permanent. Another placement in a canteen at the swimming baths had been found – but Mr J had hated this and had not pursued it. Mr J had not had any proper *'work'* or skills activity since 2003. Mr K said that he had asked for Mr J to be *'educated'*, so that he could keep his skills and his self-esteem up. Mr J's mother had died in 1998, and then in 2003 a support worker, with whom Mr J had had a very good relationship and whom he had considered *'a friend'*, had left his post working with Mr J within the Coquet Trust. These events had been a big blow to Mr J and, combined with the loss of his office placement in 2003, and being informed that he would never learn to drive (a cherished ambition), had resulted in him sometimes being depressed. It was this that had caused his difficulties.
- 8 Mr K said that he had raised with the Coquet Trust his concerns about the amount of support that Mr J had been receiving, both with regard to the activities provided and the amount of day-to-day support that Mr J and his wife were receiving, particularly in relation to the provision of meals. The Coquet Trust had asked him to contact social services directly about this, which he had done. He had asked for more support for Mr J, and eventually this had increased from 15 hours to 21 hours per week. Mr K pointed out that Mr J and his wife could not cook and, in effect, were left for four days each week without support; he thought that this had resulted in them not having adequate nutrition.
- 9 Mr K said that Mr J had thought the world of his wife, Mrs N, and that being together had been very important to them. Mrs N had been less outgoing and active than Mr J, and this had impacted on Mr J to some extent. Like Mr J, Mrs N had a strong personality and was very clear about what she wanted or liked. She liked new things and had little concept of time. She could be quite vociferous and this could be interpreted as her being more aggressive than she actually was, and of understanding more than she in fact could. Mrs M thought that as time had passed Mrs N had become verbally aggressive on occasion, and had been more difficult to accommodate. However, although she could be quite forthright with Mr J, this had been a normal part of their relationship, and as they had already indicated (paragraph 6 above), Mr J had been good at lifting her mood. The family did not consider that Mrs N had posed any danger or threat to Mr J. Mr K explained that Mr J and Mrs N had often stayed with them. During these occasions they would get Mr J to exercise, to go out and he would eat well. They would do things together as a family.

- 10 Mr J had stayed with Mr K and Mrs M for a week in October 2005, and had returned to his home nine days before he had been admitted to hospital. Mr K recalled that Mr J had not been in his usual state when he had arrived to pick him up. He had appeared to be gloomy and confused, and had appeared dishevelled. However, he had improved greatly over the week he had stayed with them. Although he had been a fussy eater and had very firm tastes, he had eaten a normal diet (meat and two vegetables, which he liked); he had exercised – gone for walks and so on. His mood had improved considerably and he had returned to his old self, and seemed happy and well. There had been no evidence to suggest that he was unsafe at home.
- 11 Mr K recalled that, during a telephone conversation prior to the October visit, Mr J's wife had said that he '*was alright now*' and when asked what she had meant, had said that Mr J was '*walking ok now*'. There had been some problems with Mr J's mobility when he arrived that October. He had initially been walking slowly, with his head down, not looking where he was going, but they had addressed this with him and his gait had been back to normal by the time he returned home. There had been no sign of Mr J having any difficulty with eating when he had stayed with them. Further, there had been no indication that there had been anything wrong with him other than not having enough activities, or support with maintaining an adequate diet. Mr K said that he had not seen any indication of a decline in Mr J's cognitive or other abilities at this time. He had therefore concluded that Mr J had been depressed when he had picked him up, but had returned to his old self when provided with activity and support. Mr K added that when he had returned Mr J to his home in Newcastle Mr J had run up the stairs, sorted his post

and then come back down the stairs to wave goodbye.

The admission

- 12 Mr K said that, prior to Mr J's admission, there had been no discussion with him or other family members about any concerns that had been expressed about Mr J's condition and skill level. The family had known that Mr J had seen a community psychologist in 2002 and 2003, but had not known why, and had not been aware that the psychologist had been assessing Mr J over several years. They had not been informed that the district nurse had been involved with Mr J's case. They said that the NHS Trust appeared to be unaware that Mr J had any family. Accordingly, Mr J's admission to hospital and the healthcare professional's concerns about Mr J had come as '*a bolt from the blue*'. The family said that social services had not involved them in any previous assessments or action plans regarding Mr J. They had not been informed about any assessments of Mr J's capacity to consent, or whether he had been assessed under the MHA.
- 13 The family had first learnt that Mr J had seen Dr A and had been admitted to Northgate Hospital when a support worker from the Coquet Trust had telephoned them on the evening of the day of his admission.
- 14 Mr K said that they knew the hospital. Mr J had stayed there many years previously to provide his mother with a period of respite care. It was a gloomy place and Mr J had been unhappy there, so the family had looked after him instead. Mr K said that, if he had known about an impending hospital admission, he would have taken Mr J home with him.

15 Mr K pointed out that Mr J had not had an advocate prior to, or around the time of, his admission. He had asked for an advocate for Mr J in December 2005, but had been informed that there had been none available at that time and he had been advised to contact an organisation called Skills for People. However, they had been unable to provide a proactive advocate for Mr J, and eventually Mr J had been provided with an advocate via an independent mental capacity advocacy pilot scheme which had been in operation at the time. Mr K said that he did not understand the circumstances in which the advocate had been appointed, but he believed it had been a result of his actions. He said that she had not really consulted with them other than by telephoning them to inform them that she was Mr J's advocate. But, in any event, as he had said, Mr J had not had an advocate at the time of his admission. Mr K said that, in the notes, in the reasons given for Mr J's admission, it had been recorded that Mr J had been crying, had been pushed into a chair by his wife, and that he had been confused by these circumstances. Nevertheless, Mr K said, he did not accept that Mr J would have been happy to consent to admission.

16 Mr K said that, after being informed of Mr J's admission, he had telephoned the hospital. He recalled that he had been told not to worry – Mr J had been admitted because of depression and would be in hospital for '*a couple of weeks*' for observation. Initially, therefore, the family had been unconcerned and had gone up to see him the following Sunday. When they arrived they had been shocked by Mr J's appearance. He had been standing in a room on his own in a classic Down's syndrome pose, which was unusual for Mr J. He had appeared to be heavily

sedated. Mr K believed this to be a side effect of the antidepressant Mr J had been prescribed. He noted that Mr J had also been prescribed an anti-epileptic drug, and that this had also had a sedative effect. Mr K said that prior to this hospital admission, there had been no indication that Mr J had suffered from epilepsy. He recalled that when he had first visited Mr J in hospital he had noticed some involuntary contractions of the muscles of his right arm, which had been described as myoclonic jerks.² Mr K told us that he had witnessed Mr J having two or three of these contractions once before, but Mr J had not displayed these signs on the five to six hour excursions on which the family had taken Mr J when they visited him or at any other time when he was with his family.

17 Mr J had said '*great*' when Mr K first visited him in hospital, because he thought that Mr K had come to take him home. Mr K recalled that a nurse had told them that Mr J had been admitted for observation, but they had been provided with no other information.

18 Mr K had attended a meeting at the hospital on 1 December 2005, together with Mr J and his wife, support workers from the Coquet Trust, a senior nurse and Dr A. No representative from social services had attended. Mr J had slept throughout the meeting (the effect of the antidepressant). Dr A had said that she had not ruled out that Mr J was suffering from depression, and she was going to try another antidepressant, but that there might be something else that was affecting Mr J. The district nurse had appeared to dominate the meeting, but her role or involvement with Mr J had not been clarified. Mr K said that, despite his requests, the length and nature of the

² Shock-like contractions of a muscle or a group of muscles.

district nurse's involvement with Mr J had never been explained to him.

- 19 It was at this meeting that the family first heard about the tests and observations that were being carried out to establish Mr J's condition. Although Mr K recalled that Dr A had told them that Mr J's antidepressant medication would be changed, and they had been introduced to Dr B, the family had not been told that Dr B would be taking over Mr J's care, nor had they subsequently been consulted about this. Without any explanation, the treatment for depression had ceased and in December Mr J had been prescribed Epilim³ after he had had a seizure in the bath. Mr K pointed out that extreme drowsiness was also a side effect of this medication. The family had not been informed that Mr J might be considered as a suitable candidate for a memantine⁴ trial. Mr K said that Mr J had been under observation to identify the effects of the medication he had been prescribed, however, as the family had not been asked about Mr J's personality, skills and abilities as they knew him, the hospital did not have the necessary information to allow them to make an accurate assessment of the impact of the medication. The meeting had stopped when Mr K had indicated his unhappiness with the way the meeting had been progressing. Mr K acknowledged that he had told the nurse to 'shut up'. He later told us that at the October 2006 local resolution meeting with the NHS Trust, the NHS Trust had apologised for the nurse's behaviour at the meeting and had said that she was inexperienced.
- 20 A further meeting had taken place in January 2006. Mr K said that the family had not previously been informed about who would be

at the meeting, and they had entered the room to find that seats had been reserved for them, but that the meeting appeared to have already started. They had been shocked to learn that it seemed that the healthcare professionals had been unaware that Mr J had any family, and that Dr B had started the meeting by asking who knew Mr J best.

- 21 The family had also been shocked to learn at the meeting that, shortly after admission, Mr J had been put on a soft diet on the advice of the speech and language therapist (SALT). They had also been shocked to learn that he had been allocated a wheelchair, in case he fell. They said that, prior to his admission to hospital, Mr J had been able to walk perfectly well, cope with stairs and eat normally and that he had continued to do all these things after admission when the family had taken him out, but this appeared to have been ignored. The family said that they were convinced that the combination of medication side effects, and the assumptions that had been made about Mr J's mobility and condition, had together resulted in his being treated in hospital in a way that had seriously damaged his ability to maintain his skill and ability levels.
- 22 The family had asked for a second SALT opinion relating to Mr J's diet, but this had been refused; no grounds had been given for this refusal other than that it had not been considered necessary. Mr K said that he had handed in a film which he had taken shortly beforehand of Mr J happily eating crisps without choking which showed that he did not need a soft diet, however this had since been lost. Mr K said that the soft diet Mr J had been given, namely minced fish or chicken leg, would have been particularly

³ An anti-epileptic and mood stabilising drug.

⁴ A drug used to treat moderate to severe Alzheimer's disease.

- unappetising for him, given how fussy he was about his food. Nor did it appear that Mr J had been given much choice, or provided with many opportunities to engage in activities. No risk assessments had been discussed with them, nor had they seen any OT plan of activities for Mr J whilst he was in hospital.
- 23 Mr K said that they had not been informed about the OT visit to Mr J's flat after his admission to hospital to assess the risk levels. The family had noticed that the support worker's recollection of events about Mr J's behaviour and skills at the time of the assessment differed from that recorded in the OT's assessment. However, they had also noted that he had, despite his stay in hospital and reduced physical activity, still been able to get up and down the stairs without any problem.
- 24 Mr K said that Mr J had been greatly distressed by his continuing stay in hospital and unhappy throughout his time there. He had clearly indicated that he wanted to go home to his wife. He was aware that Mr J had spent at least one day crying and just saying the word 'home'. Mr J had been locked in at the hospital, and the family had not been allowed to see his bedroom there. Mrs N had not been able to visit Mr J very much; the Coquet Trust workers had taken her to the hospital, but they had had to get there by public transport, which had meant taking two buses. The journey time took about two hours and this had eaten into the support time that had been allocated. Mr K said he had not been informed about how the support hours that had previously been allocated to Mr J by social services had been used. Mr J had been asleep most of the time he was in hospital and when the Coquet Trust workers had arrived with Mr J's wife they had apparently let him sleep, instead of taking him out to exercise and get fresh air, and taken Mrs N to the canteen.
- 25 Mr K said that he suspected that Mr J had had low blood pressure, both when in hospital and when he had moved to the care home. Mr J's feet had often been blue and Mr K had had to rub them to get his circulation going. Mr K also said that in 2003 Mr J's toe nails had been allowed to get overgrown to the point that they had been like claws and that this had affected Mr J's mobility. He had personally cut Mr J's toenails when Mr J had visited him as they had been equal to a whole shoe size. Mrs L recalled that sometime prior to Mr J's admission she had asked for a chiropodist to attend to Mr J, but that this had not materialised. They had then privately arranged for a chiropodist to attend to Mr J's feet. Mr K said that when Mr J went to live at the care home his nails had returned to a claw like state.
- 26 No one had suggested to the family that Mr J could stay with them temporarily to give him a break. In fact Mr K had indicated to the hospital that Mr J could stay with them temporarily, but no one had followed this up, and Mr J had not been allowed to spend Christmas with them. They had also been informed by social services, after Mr J had moved to the care home, that he and Mrs N could not have a short holiday with the family. This had apparently been on the grounds that Dr B had thought that a new environment would not be beneficial to Mr J. Mr K and his wife noted that Mr J and Mrs N had often stayed with them for short breaks over a period of many years and had consequently been familiar with their home, and the surrounding area, including the neighbourhood and town. In the light of this, they considered that not allowing Mr J to stay with them had been a particularly cruel decision and amounted to a denial of family life

for them and for Mr J. Mr K later told us that Mr J could have stayed with him and his wife permanently, but they had never been given a chance to discuss the matter.

- 27 The family said that they had not seen a copy of the CT scan. They had not been aware that Mr J needed glasses and had been doubtful whether they were right for him. Mr K said that Mr J seemed to use them as a fashion accessory, but that he had enjoyed cleaning them, which he was always doing.
- 28 Mr K said that it was his view that concerns about Mr J apparently raised in 1998 by the Coquet Trust had resulted in him being labelled as having dementia – consequently, other possible causes of his symptoms had been overlooked. Mr K said that they had not been aware of any concerns; all reports and discussions about Mr J with the Coquet Trust had been positive and complimentary.

The role of social services

- 29 The family said that social services had not communicated with them at all, even after they had raised their concerns about Mr J's situation and had made it clear that they wished to be involved and kept informed. As they understood it, social services would have been expected to have included and involved the family fully, and to have been far more proactive in intervening and providing more leverage on Mr J's behalf. This had not happened and consequently the family had been excluded and not given the opportunity to provide information that would have been key to assessing Mr J properly. Mr K considered that social services had failed to act in Mr J's best interests. He said that he believed that, had Mr J received the right support, and been

properly assessed taking account of the family's knowledge of him, Mr J would have had a better quality of life whilst in hospital and in the care home, and would have still been alive today. Instead, the quality of Mr J's life had been poor and he had been deeply unhappy.

- 30 Mr K said that he was aware that social services had been seeking alternative accommodation for Mr J. He had privately tried to contact a local authority housing officer about Mr J's situation. Mr K said that he had not been informed that Mr J had been registered with Your Choice Homes in Newcastle, and he had been unaware that Mr J could, once registered, have nominated someone to look for accommodation for him. The family recalled that in March 2006 they had been told that the care home had been identified as a possible temporary housing solution. They had been informed that it was self-contained, but that had not been the case. It was on the second floor in a home for the elderly and the stair and lift access were locked, because of concern that Mr J might try to access these and might fall. He was therefore effectively locked in. It was also difficult for the family to get access – access to Mr J's flat could only be gained through the care home and the entrance to that was locked. The family had had to sign in and out when they visited. There had also been no landline in Mr J and Mrs N's flat. Mobile phones were provided, but these were expensive to use and were often switched off; Mr J would also lose or break them. This meant that the family had found it very difficult to communicate with him. Nevertheless, neither the social services, nor the Coquet Trust, had made any real attempt to facilitate Mr J's communication with his family.
- 31 Mr K said that he had indicated to Mr J's wife that the care home was unsuitable for them. However, she said that she had been told that if

she did not agree to the care home, Mr J would not be able to leave hospital. Mr K thought that this had put pressure on Mr J and his wife to accept an unsuitable property. Given their learning disabilities, he considered that that had been inappropriate and amounted to manipulation.

- 32 Mr K said that Mr J and Mrs N had not needed 24-hour support (as provided in the care home); they needed to be returned to their old home or moved to suitable accommodation and provided with appropriate support that would allow them to live as independently as possible and keep Mr J's skill and activity levels up. Mr K added that, in order to provide 24-hour support, many different workers had been attending and that this had meant that they had been unable to build up helpful relationships with staff. As it was, Mr J had been very unhappy at the care home and had frequently been tearful. Further, the limitations of the accommodation had not helped Mr J's and his wife's relationship.
- 33 Mrs M recalled that a neighbour would have been happy to have let ground floor accommodation to Mr J and his wife. However, they understood that the accommodation had been turned down because it had been at market rent, which had been too expensive. Mr K recalled that after Mr J had moved to the care home one of the workers there had been keen for him to return to his old flat and had been exploring the possibility of installing a stair lift.
- 34 Mr K said that he was very dissatisfied with the way that social services had handled his complaint. First, the 24 points considered in the Stage 2 complaint had not been his; secondly, the family had not been interviewed, although they had wished to be; and thirdly, not all

of the relevant staff had been interviewed. Mr K said that he did not accept that the geographical distances and the amount of written material made it unnecessary to interview them. Finally, he had not been happy with the findings or with the fact that the time taken to investigate the complaint had meant that the main focus of the complaint, which had been to get Mr J out of hospital and then out of the care home, had become unachievable.

- 35 Mr K said that the family were also not entirely happy with the outcome of the Stage 3 panel's review. They considered that social services had wrongly been exonerated to a large extent. Mr K pointed out that the family had not been told what action social services had taken to ensure that families were communicated with appropriately in cases such as theirs, despite that being one of the Stage 3 panels recommendations. Nor had they been informed as to whether Mr J's case had been brought to the attention of the social services inspectorate, which had been another recommendation.

Mr K's further comments on events on 6 and 7 April 2007

- 36 Mr K said that Mr J had appeared to be fine when they had spoken on the telephone in the early evening of 6 April 2007. When a carer from the care home telephoned the next day to say that Mr J was being admitted to hospital he had indicated that Mr J was not seriously ill and would be out in a few days. When Mr K arrived at the hospital he had been shocked by Mr J's condition. He really wanted to establish the facts, as far as possible, about what had led to Mr J's sudden admission to hospital, when he had seemed well shortly before admission.

Mr K said that he was aware that carers were not medics, but he needed to know the course of events.

Annex D – Comments from Dr A and Dr B

Dr A

- 1 Dr A, who has since retired, told us in her written response that she had provided consultant input at the NHS Trust for adults with learning disabilities from 1999 onwards. She had not had responsibility for the geographical sector in which Mr J lived. However, at the time of Mr J's admission there had been no consultant psychiatrist in post for Mr J's area so she had agreed to provide emergency cover. She had been unaware when she had been working at the NHS Trust that there had been a complaint regarding the care and treatment provided to Mr J. Her only recollection was that a manager had briefly asked her why Mr J had been admitted. She said that her comments were therefore based on the limited documentation she had been provided with and her recollection of the events which had taken place several years previously.
- 2 The NHS Trust had a part-time specialist in old age psychiatry whose remit included patients with Down's syndrome aged over 40. Urgent referrals within this category would be picked up by a sector consultant and then referred to the specialist concerned. This was standard practice in psychiatry, where care was divided by specialities and geographical sectors, and in any situation where a consultant provided responsible medical officer (RMO – under section 12 of the MHA) cover. It was not usual practice to document such handovers in the medical notes or to obtain specific consent from the patient or relatives for such a handover.
- 3 Dr A said that she had decided on a rapid assessment because Mr J's GP had made an urgent referral regarding Mr J's declining condition. Mr J's wife had not attended on 11 November 2005, and little background information had been available, although she had been aware that the Coquet Trust provided some support. Dr A said that she had not been informed that Mr J had been regularly reviewed for several years by the Consultant Clinical Psychologist, or that an urgent referral had been made to speech therapy regarding concerns about episodes of choking. Nor had she been aware of the multidisciplinary referral and assessment in October 2005. Her initial impression had been that Mr J had a depressive illness.
- 4 After she had seen Mr J she had spoken to a nurse from the CLDT, who was also Mr J's community nurse. The nurse had not been present at the appointment because Dr A had been unaware then of the nurse's involvement and no one had told the nurse about the referral.
- 5 The nurse concerned had informed her that recent attempts to assess Mr J had been unsuccessful because Mr J had '*slowed up*'. Dr A said this could be symptomatic of psychomotor retardation or severe depressive illness. Because the information provided about Mr J's deterioration in functioning indicated a possibility that he was severely depressed, she had started him on half the therapeutic dose of an antidepressant with minimal side effects. This was necessary because Mr J's carers had given a history that was consistent with myoclonic epilepsy; it was usual practice to start people with learning disabilities on a reduced dose because they may be more susceptible to side effects. The plan was to increase the dose when Mr J was next seen. Dr A added that myoclonic epilepsy could also be a symptom of an Alzheimer's type dementia in people with Down's syndrome.

- 6 Dr A went on to say that she had given the community nurse a prescription and asked her to discuss the medication and any possible side effects with Mr J, his wife and carers and to organise a Medipack (a compliance aid) to simplify administration. She would normally have discussed this with the patient and carers herself, but had been unable to do so on this occasion because Mr J had already left the hospital site. As the community nurse was a senior and experienced nurse and Mr J was well known to her, Dr A did not consider this plan to be inappropriate.
- 7 The community nurse subsequently asked her to review Mr J urgently a few days later on 16 November 2005. Mr J was said to have deteriorated further; in addition, he had not been eating or drinking (which might also be symptomatic of depressive illness).
- 8 Dr A said that, although she had been informed that Mr J had lost weight, he had not initially presented as underweight. However, on 16 November 2005, she noticed that the waist of his trousers seemed too big, suggesting that he had previously been overweight.
- 9 That day, Mr J had spent over two hours in her clinic. He had been extremely distressed and it had been evident that Mr J's wife was anxious about his condition and found Mr J's deterioration hard to cope with. It was clear that there had been a major deterioration in Mr J's condition since she had last seen him; it was very unlikely that this could have been caused by the sub-therapeutic dose of medication dispensed two days previously.
- 10 Dr A said that it was unclear whether Mr J was suffering from a severe and major depressive illness; early symptoms of dementia; the effects of an intracranial lesion, such as a chronic subdural haematoma;¹ or whether there were any other unidentified significant factors. Admission for further assessment was therefore required.
- 11 Dr A said that she had considered contacting Mr K, who lived some 80 miles away, but given the available information, and Mr J's and his wife's distress, she had considered it of paramount importance to find Mr J a place of safety. The only beds to which she had access were in Northgate Hospital or another learning disability hospital some distance from Mr J's home. The chances of obtaining a bed were limited; however, a bed had become available at Northgate late in the afternoon of 16 November 2005; she knew from experience that if she did not take the bed it would probably be reallocated to another emergency during the night.
- 12 The options available to her that day had been:
- If Mr J, his wife and carers were in agreement she could have immediately admitted him to hospital for assessment. This option would allow Mr J (and his wife) to be taken first to look around the ward by the community nurse.
 - If Mr J had not been agreeable to admission, assessment under the MHA would have been necessary. This would have been difficult to organise, as she could not have called on other learning disability psychiatrists for a second medical recommendation because

¹ A collection of blood (haemorrhage) over the surface of the brain, commonly caused by trauma, but can be spontaneous. It often requires surgical intervention.

they covered a different geographical area. In her experience it would have taken several hours to locate another mental health psychiatrist who would be willing to undertake the assessment. Although it was evening surgery time she did not telephone Mr J's GP to ask him to attend, because the building in which her clinic was situated closed at 5pm. She did not consider it appropriate or safe for her to stay in the building alone with a very distressed patient and a disturbed relative.

- She could have sent Mr J home with his wife, who was behaving rather aggressively. However, she had also been aware that Mr J could wander at night (because it was recorded that he had been brought home by the police). It was already dark, and she had been concerned that Mr J might not be at home if she arranged for an approved social worker, the consultant on call and another psychiatrist and/or Mr J's GP to see him. Additionally, that would have meant that Mr J could have been taken to hospital at night by strangers.
- 13 There had also been the possibility that, as Mr J had agreed to admission, an approved social worker would not have agreed to detaining him under the MHA. It had been unclear at the clinic whether Mr J had capacity to consent to admission. He had been so distraught and mentally slow that any formal assessment had not been possible at the time. When the options had been discussed with him, his wife and carers it seemed that the best one was to view the hospital, meet the staff and see if he was prepared to stay there.
- 14 Dr A had not been present at the admission. The community nurse had provided Mr J with transport and support. The admitting officer had documented that Mr J '*was happy*
- to stay*'. Dr A considered this was a practical demonstration of Mr J's capacity to consent to admission after he had seen where he would sleep, who would be looking after him, the physical environment and other patients. Not only did this demonstrate to her that Mr J had had capacity in this matter, but it had also, in her view, been an excellent demonstration of giving patients concrete choices, in contrast to relying on a presumed facility for abstract thought, which could be discriminatory. Dr A said that it was important to remember that the law then, as now, made a presumption of capacity.
- 15 The assessment of capacity had not been static, but was an ongoing process that was specific to the choice being made. Dr A said that it would have been contrary to her normal practice, or that of nursing staff, to ignore a request to leave or to '*persuade*' a patient to stay against their demonstrated will.
- 16 Dr A acknowledged that she could have chosen to assume that Mr J lacked capacity, because he was in such a state of catastrophic distress, and proceeded with assessment under the MHA. However, guidance stated that there should be an assumption that the patient possessed capacity until shown otherwise. She considered that to have compulsorily detained Mr J under the terms of the MHA might have been discriminatory, given that he might have had capacity to make a valid choice when in a safe place and not overwhelmed by distress. To support that view, she noted the contrast between Mr J's clinical presentation in the late afternoon of 16 November and that on 19 November 2005, when it was recorded that he had enjoyed a TV programme about dancing and had asked a nurse for a dance. She considered that it would have been invalid

- to have formally assessed Mr J's capacity on 16 November alone in the circumstances.
- 17 That said, had Mr J not agreed to admission, there had been, in her view, grounds to detain him under the MHA. These were: safety, given the available history; the significant and rapid deterioration in his mental health; loss of weight; refusal to eat or drink; wandering; history of falls; extreme distress; and his wife's difficulty in coping with his deterioration.
- 18 Dr A said that she would usually have documented in her notes that, if Mr J expressed a wish to leave the hospital, he should be assessed under the MHA. She had not done this at the time because of the urgent need to get Mr J to a place of safety, and the medical notes needed to accompany him to the hospital. In an ideal world she would have made additional telephone calls. She could not recall whether she had had Mr K's contact details. It would not have been possible to arrange for someone to stay with Mr J overnight at his home and reserve a bed for the following morning, because there was no person immediately on hand to provide such care. Social services would have seen this as a medical (as opposed to a social) problem and there was no out-of-hours community care available via the NHS. If care staff had been available, they would not have been able to prevent Mr J wandering. Any scenario other than admission would have resulted in Mr J being further traumatised and/or at risk.
- 19 The community nurse who had accompanied Mr J to hospital was able to witness whether he was willing to stay; and one of the duties of the admitting officer was to contact the next of kin. Although Mr J's wife was his next of kin, Dr A had been sure that his wider family would be contacted.
- 20 Dr A said that her normal practice when admitting a patient in an emergency was to telephone the ward later that evening or early in the morning, before the night staff went off duty, so that she could get a first hand account of the patient's mental state and any concerns. If she were on duty the next day, she would contact the day staff. In any event, staff were aware that, if they had any concerns, they could contact her. She noted that the documentation she had seen did not indicate that Mr J had expressed a wish to leave, or tried to leave, or that Mr K had requested a discharge. If this had been the case, Mr J would have immediately been assessed under the MHA. Almost certainly, she would have detained him within the terms of the MHA unless suitable alternative arrangements had been made, such as Mr J staying with Mr K, but with 24-hour care and twice daily assessments being available.
- 21 Moreover, she had arranged for Mr J to be assessed for an intracranial lesion as a possible cause of his symptoms. Arranging a CT examination had taken several hours by telephone. She could not have managed this on an urgent outpatient basis, and arranged transport and escorts, and attended her other patients.
- 22 Other investigations (blood tests to exclude problems with hydration, vitamin deficiency, thyroid problems, anaemia) had been organised as a matter of course. An urgent EEG had been arranged due to reports of fits; and an urgent dental appointment, regarding difficulties with chewing and swallowing. It would have been difficult to organise these urgently on an outpatient basis. Moreover, it had been essential to have an ongoing assessment of Mr J's mental state and behaviour via 24-hour observation.

- 23 The records indicated that there was a marked variation in Mr J's mood during the course of the day. He had been very unresponsive in the morning, but more alert in the late afternoon. Such symptoms could indicate depressive illness; but where there was also evidence of confusion, it could also give rise to a clinical presentation consistent with dementia – a pseudodementia. She had therefore increased the antidepressant medication to a therapeutic dose. However, after seven days Mr J had become very sleepy and there was evidence of low blood pressure, both possible side effects: she had therefore discontinued the medication for baseline assessments of blood pressure, mental state, and fit frequency.
- 24 The specialist in the psychiatry of old age had been unable to attend the CPA meeting on 1 December 2005. Dr A said that she had not asked at that meeting who had known the patient best, as Mr K had suggested (paragraph 19 of the report). The meeting had concluded that Mr J's care would be formally transferred from Dr A to Dr B from that day onwards and that social services would be contacted regarding the urgent need for accommodation and probable 24-hour support. Dr A said that she had explained to Mr K during the meeting why the antidepressant medication had been stopped (as in paragraph 24). Dr A had indicated that she would leave Mr J off all psychotropic medication until he had been seen by Dr B. She also recalled a long discussion with Mr K after the meeting regarding the possibility of early onset, Alzheimer's type, dementia in someone with Down's syndrome.
- 25 Dr A said that she had not diagnosed dementia, nor had she made any other formal or definitive diagnosis, as she handed over care early in the assessment. This would have been made clear at the CPA meeting. Keeping Mr J off medication until baseline assessments could be made, and discussing the possibility of early onset dementia with Mr K, had been good practice.
- 26 She recalled the community nurse making arrangements for the CLDT to provide transport for Mr J's wife to visit him; that would be impossible to arrange for all inpatients.
- 27 Dr A said that she believed that she had provided Mr J with a good standard of care and had made strenuous efforts to ensure that he was not discriminated against; she made every effort to exclude any underlying physical or treatable cause for the deterioration in his condition and mental state. Dr A concluded that formal responsibility for Mr J's care had passed to Dr B on 1 December 2005, and she had had no further involvement with his care subsequently.

Dr B

- 28 Dr B said that a letter that she had written on 18 January 2006, to Mr K's sister, had dealt with the issues raised in his complaint. In her letter she had noted that she had been unable to address questions raised at Mr J's review on 12 January 2006. She had apologised that the meeting had had to be interrupted. Knowing that Mr J's family wished to discuss their concerns, she had thought it more appropriate to wait until she met them, rather than gather information over the telephone. She had background information from other professionals and carers. There was evidence that Mr J had developed dementia. Difficulties with chewing and swallowing food were also common, and this risk had been highlighted following a referral to the SALT. The soft diet was to reduce the risk of choking or aspirating food, which could be fatal. It was sometimes

difficult to establish whether symptoms were a consequence of depression or dementia. It had been established that Mr J's symptoms were due to dementia. He had also developed myoclonic epilepsy, which was common in people with Down's syndrome when they developed dementia. Mr J had experienced side effects from the antidepressant medication initially prescribed, and there had been no clinical reason to restart the medication, given his diagnosis. The multidisciplinary team had Mr J's best interests in mind, and his needs had been addressed as they emerged.

Annex E – Professional advice obtained

Psychiatric Adviser

The assessment of Mr J's capacity to consent to care and treatment

1 The *Mental Capacity Act 2005* (MCA) was not fully implemented until after Mr J's death. At that time no other person could consent for someone who did not have the capacity to consent to treatment.

2 DH guidance issued in 2001 introduced a consent form for adults who lack capacity to consent to a particular treatment (Annex B, paragraph 31). It stated:

'...As no-one else can give consent on behalf of such a patient, they may only be treated if that treatment is believed to be in their "best interest". This form requires health professionals to document both how they have come to the conclusion that the patient lacks the capacity to make this particular healthcare decision, and why the proposed treatment would be in the patient's best interests. It also allows the involvement of those close to the patient in making this healthcare decision to be documented.'

3 In 2005 clinical assessment had not required documented formal assessment of capacity, and clinical practice varied. However, good practice in 2005 would have required the clinicians involved to consider and document whether Mr J had understood what was being proposed and that he was willing, albeit reluctantly, to comply with the recommended admission. Consideration should also have been given to whether he retained capacity during his admission to give his consent to remain in hospital, particularly as Mr J's condition was apparently deteriorating. The assessment of capacity was clearly not a static process.

4 A report of the outpatient assessment with Dr A in November 2005, at which his proposed admission was discussed with Mr J and his wife, acknowledged their reluctance but confirmed their acquiescence after a lengthy discussion. I assume that Dr A had decided that Mr J did have capacity at that point but she did not document this. Later in his admission it is clear that someone had decided that Mr J did not have capacity: part of the CPA process at Northgate Hospital included a requirement to document the service user's agreement to sharing information with professionals. This was incompletely filled out in the clinical notes and in all cases simply said he could not give his consent, clearly, therefore, the guidance in paragraph 2 above was not followed in this case. I consider that the NHS Trust were in error in not documenting the steps taken to assess Mr J's capacity and to explain what measures they had taken to ensure his best interest, including consulting his family and carers.

5 Although I have seen that Mr J's wife, as his next of kin, was consulted about his admission, I consider that it would have been good practice to consult his wider family urgently at this point, particularly given that Mr J's wife had a learning disability herself and therefore may not have fully understood what was being proposed.

The standard of care and treatment provided to Mr J

6 I consider that generally the overall level of treatment Mr J received from the NHS Trust did not fall below acceptable standards.

7 The following examples show how thorough Trust staff were in trying to meet Mr J's healthcare needs.

- Early in September the deputy support team manager from Coquet requested a multidisciplinary assessment by the CLDT. Mr J was put on a waiting list on 15 September. A report jointly signed by occupational therapist (OT), psychology, speech and language therapist (SALT) and Physiotherapy was finalised in late October. This report concluded that Mr J was showing signs of cognitive decline and that his care package needed to be revised in the light of his increasing needs.
 - In addition Mr J was assessed by professionals from four disciplines and a community nurse and a consultant psychiatrist also assessed Mr J before admission. There was considerable concern about his safety because of reported falls at home, and because of concerns about the stress his condition was causing in his relationship with his wife. To carry out the investigations needed to properly assess him on an outpatient basis would have been difficult. In addition, social services would have had to provide an immediate and substantial increase in his care package and urgent rehousing. In my opinion, an admission for assessment does seem to have been the only possible decision in the circumstances.
- 8 However:
- With respect to medical involvement in Mr J's care, a neurology assessment in 2003 was inconclusive with respect to epilepsy, but an epilepsy liaison nurse was appointed to work with Mr J and his carers. There was no medical or psychiatric involvement other than by his GP following this until September 2005 when his GP referred him to a consultant psychiatrist – although in 2004 the psychologist had also recommended that a consultant psychiatrist at Northgate Hospital should assess Mr J. There is no record of this having taken place.
 - It is good practice to send copies of letters to the patient and, with their permission, to carers and family members. Such letters clearly have to be written in a straightforward way and someone needs to be alerted to the need to read the letter to a patient who cannot read.
 - One note by the community nurse is an undated summary of a health check, completed possibly in October 2005. The purpose of this assessment was not clear. It does not seem to meet the expected standards of a health action plan to which Mr J was entitled (Annex B, paragraph 26). Mr J would have been able to invite his family to be involved in developing his Plan if he had wanted to. This would have kept them informed about his ongoing health needs. Given the concern about his deteriorating health, I am surprised that such a meeting does not appear to have been set up. Mr K complained that he did not know that the community nurse was seeing Mr J regularly (although the nurse would have had to ask Mr J's permission before contacting his family).
 - The CPA meeting records were incomplete, often undated and unsigned. The earlier meetings were poorly attended and did not cover the range of needs required by the DH guidance on the CPA. The 'service user/carer views' section was not completed.
 - Serious problems began to arise when discharge was delayed because of a lack of suitable alternative accommodation after it had been clearly established that Mr J's own home was no longer suitable for him. This delay was unacceptable.

Assumptions about Mr J's symptoms because he had Down's syndrome

9 I am of the view that appropriate consideration was given to other possible causes of Mr J's condition. In coming to this view I have seen that:

- Investigations identified that Mr J was hypothyroid and this was treated.
- It was also considered that he suffered from postural hypotension (low blood pressure), which would have contributed to his falls. Advice on the management of this condition was provided in his notes.
- Mr J had an eye test, although it is recorded that he did not like to wear glasses.
- Although Mr J was only in his early fifties, it is well known that people with Down's syndrome age prematurely and the expertise of geriatricians can sometimes be helpful – this was considered by his GP, who concluded that it was not appropriate.
- There is enough evidence from the medical notes that Mr J did have dementia, which is a very distressing condition for everyone who cares about an individual as well as for the person himself. He had deteriorated considerably by the time of his final admission in April 2007 when the consultant physician noted that he was doubly incontinent.

Whether Mr J's communication difficulties (including his large tongue) and his usual behavior were properly taken into account

10 Northgate is a specialist learning disability hospital and all of the staff would have been used to working with and communicating with people with Down's syndrome and learning

disabilities. All of the other patients would have had learning disabilities. There is nothing in the papers that I have seen suggesting that his condition was not taken fully into account.

The decision to put Mr J on a soft diet at the time of his admission

11 This is a precaution taken because of the increased risk of choking in people with Down's syndrome, particularly when starting psychotropic medication. It seems a reasonable decision during a period of assessment and whilst he was commencing new medication. The risk of aspiration pneumonia would have been a concern, and I note that Mr J may have had a chest infection in 2006 attributable to aspiration, and his death was attributed to aspiration pneumonia. Often aspiration is silent and not identifiable by the patient or his carers. I could find no evidence of episodes of choking, but there is evidence that the care staff had received training and support from both the SALT and the dietician about this potential risk as well as to address their concern about his loss of weight.

Request for a second opinion regarding the SALT assessment

12 Best practice usually involves seeking a second opinion when it is requested. I found a record of a senior SALT being asked by Mr K by telephone in December 2005 to review the recommendations of her colleague. This manager did review Mr J's care and concluded that the SALT's advice and care plan was correct. The later decision not to seek another opinion was because Dr B considered it clinically unnecessary. Whilst another (*third*) opinion could have been sought, given the

concerns of the family, the treatment Mr J received sounds at least standard if not above average. I was pleased to see that a SALT had been consulted and had assessed the risk of dysphagia and continued to be involved in monitoring his care and training his carers until the time of his death. People with Down's syndrome are at increased risk of swallowing difficulties and this risk is increased when drug treatment for depression and sometimes for epilepsy is introduced. Swallowing difficulties are also associated with dementia in some people.

The side effects of the medication that Mr J was prescribed on admission – effects on his skills and abilities, including mobility

- 13 Nausea, headache, tiredness and dizziness, insomnia, constipation and loss of appetite are some of the side effects described for Escitalopram (an antidepressant). Less common effects have been reported on blood pressure. Mr J was started on a low dose of 5mg, which is good practice in someone with Down's syndrome, rising to 10mg after a few days – the normal recommended starting dose is 10mg. This medication was discontinued after a short period, and the reason given was that he was not showing signs of depression. I note that there was also increasing evidence that the primary diagnosis was dementia. The EEG and the CAT scan, supported by the psychological and speech therapy assessments, confirmed this.
- 14 Side effects of sodium valproate (an antiepileptic drug) include a decreased appetite, weakness, drowsiness, skin reactions and, rarely, blood production disorders. Mr J's starting dose was 300mg, which is unremarkable; this was increased to 400mg

and later reduced to 200mg. I could see no explanation for the changes in dose but I presume that they were related to his symptoms. I note that it was reported that Mr J appeared more alert after this medication was reduced. In October 2006 this medication was discontinued because of anaemia and replaced with topiramate. It seems that the medication was being monitored but the records I have seen do not provide enough information about the thinking involved in the changes to his medication.

The provision of appropriate activities during Mr J's stay in hospital

- 15 It is not usual for someone to have similar activities to their usual programme during a hospital admission of a few weeks for assessment. Mr J was offered art and drama therapy and his care plan included working on his personal hygiene, social training and recreation. In my view, once he was considered ready for discharge his programme of activities might have included more community visits with his wife, thus preparing him for his return home. I consider that his delayed discharge was very unfortunate and the eight hours of support being provided by social services to enable his wife to visit him once or more each week does not seem enough.

Whether the admission was detrimental to long-term psychological and physical health, as it exacerbated the loss of skills and abilities

- 16 Admission to hospital was clearly a distressing event for Mr J. In my view, this would have been disorienting for him, and discharge to a new home even more so. I think that the staff

who took the decision to admit him were aware of the importance of this decision and it was based on their opinion that he was at serious risk of injury or death if he stayed at home without significant changes to his accommodation and support. In this situation either a decision to admit or one not to admit could have contributed to deterioration in his physical and mental health. It is important to recognise that Mr J was suffering from a life-limiting and deteriorating condition. It is difficult to separate the impact of the admission on his psychological and physical health and the natural course of his dementia. However, given the situation, I am of the view that it was not possible to have avoided admission to hospital in Mr J's case. In coming to this view I have taken the following into account.

- 17 The only viable alternatives would have been to have immediately provided 24-hour care for Mr J at home whilst seeking to provide ground floor accommodation for him and his wife, and to have provided an intensive home assessment and continuing community treatment by a multidisciplinary mental health team. In reality, co-ordinating such an outcome quickly would have been impossible unless the NHS Trust had such a team already established.
- 18 That said, if a multi-agency case conference had been held with the extended family and with Mr J and his wife, these options could have been fully explored. It is possible that his family might have offered temporary accommodation for Mr J and his wife whilst new accommodation was being found.
- 19 Furthermore, Mr J needed urgent medical investigations as mentioned and it would have been difficult to co-ordinate such assessments and assess him fully if he remained at home.

A careful reading of the medical records and correspondence clearly indicates that Dr A's intentions were to admit Mr J for a time-limited period of investigation. He was admitted on 16 November and judged ready to be discharged on 12 January 2006 – just eight weeks later – only two weeks longer than anticipated by Dr A. I consider that this was reasonable.

- 20 In January 2006 he was assessed at home by a senior occupational therapist and in my opinion her report is detailed and persuasive in its conclusions. It then took a further five months to find and equip suitable accommodation. This was clearly very unsatisfactory, especially given the seriousness of Mr J's condition. The challenge in such a situation is always to retain the close involvement of social services once a patient has been admitted.
- 21 I note that Mr K was advised that Mr J should not, on medical grounds, stay with him for a short holiday. In my opinion the explanations for not allowing Mr J to go and stay with Mr K are unsatisfactory, especially if Mr J had expressed a wish to accept his brother's invitation, or if Mr J was not consulted about this invitation.

Additional comments:

- 22 In addition:
 - The record keeping at Northgate Hospital was variable in quality, with some reports (particularly nursing reports) being undated and unsigned. Others were excellent: detailed, informative and well written.
 - It is still unusual for people with learning disabilities to form lasting intimate relationships and to be supported to marry. This suggests that Mr J and his wife had

considerable personal coping resources and stable personalities. Mr J's next of kin was his wife, and staff would have been correct in considering that their primary responsibility was to inform her and seek her opinion. However, she also had a learning disability and her capacity to be involved in decisions about Mr J's care would also need to have been considered. I am concerned that she was only supported to visit Mr J weekly, which suggests that their relationship as man and wife was not being given full consideration. Also, despite reported concerns about their relationship at the time of his admission, I found only one comment in the hospital records about their relationship – the drama therapist in February 2006 noted that Mr J brightened up in the presence of his wife.

- Communication seems to have been poor between all of those who had responsibility for Mr J's care. For someone with complex healthcare needs and a long-term care plan, these communication failures were unacceptable.

Conclusions

23 Overall:

- It was the responsibility of those caring for Mr J to inform the clinicians about the family background so that they could be involved.
- The wider family were inadequately consulted. A family meeting, or at least a telephone conversation, should have taken place before his admission. This became a significant factor in later disagreements about Mr J's care.
- The NHS Trust were in error in not documenting the steps taken to assess Mr J's capacity and not explaining what measures

they had taken to ensure his best interest, including consulting his family and carers.

- More effort should have been made to support Mr J spending more time with his wife.
- Record keeping was incomplete. Best practice would suggest that the NHS Trust should consider routinely copying reports to the service user, their next of kin or another close relative, as agreed with the service user or their advocate.

Nursing Adviser's comments

- 24 Regarding Mr K's specific concern about the care provided to Mr J in the days immediately preceding his death, the Nursing Adviser noted that there were very few entries in the records, but there was no suggestion in those that an imminent, very serious or fatal decline, had been missed or not prevented.

Annex F – Chronology of key events

1992 – 2003

Mr J had Down's syndrome. He was an active, outgoing and sociable man who had originally lived with his mother, but from 1989 onwards had lived independently in the community; from 1992 onwards this was with his partner, Mrs N (who also has learning disabilities), whom he married in 1996. Day-to-day support to help Mr J and his wife maintain their independence in rented accommodation was provided by the Council; from 1995 onwards this was through a contract with the Coquet Trust, who provided local support workers. In 1998 Mr J's mother died. In 2003, one of the carers who had been providing support for Mr J for a long time, and whom Mr J considered a friend, moved away from his role as Mr J's carer.

Until 2003 Mr J had had a work placement in an office doing photocopying two days a week, but this was terminated when it was considered that Mr J could no longer cope with it. (No other placements were found for Mr J, other than helping out for a few hours a week in the Coquet Trust office, until the autumn of 2005.)

2004

During 2004 a consultant clinical psychologist, who had assessed Mr J on several occasions since 1998, concluded that Mr J could be suffering from a loss of skills associated with a process of early ageing.

7 April: The Coquet Trust requested funding for more support hours for Mr J (which were then 15 hours each for him and Mrs N) from social services, due to concern about changes in his behaviour and a deterioration in his abilities.

30 July: Social services assessed Mr J.

3 November: The Coquet Trust requested an update from social services.

2005

During much of 2005 social services and the Coquet Trust corresponded about Mr J's support needs, with the latter pressing social services to fund extra hours in response to the continuing decline in Mr J's skill levels and functioning. They raised particular concerns about his mobility problems (increasing unsteadiness and his wife had reported that he had had falls), changes in mood and memory difficulties, which meant that many tasks took longer for Mr J to complete and that he needed repeated prompting.

4 April: Mr J was reviewed again by social services. Social services disputed (in April/May) that Mr J needed increased support.

3 September: The Coquet Trust's service manager wrote to Mr K regarding the outcome of a meeting that had been held with social services to review the support provided to Mr J. The service manager said that it had been agreed by social services that Mr J and his wife would be allocated a nominated care manager, and that more support around meal preparation and activities for Mr J would be provided. Social services would also try to find Mr J suitable employment. He hoped that the agreed action would allay some of Mr K's concerns and noted that:

'undoubtedly there have been lapses in the past from the high standards which you are entitled to expect, and which the Trust sincerely aims to provide, and it is not inconceivable that others may occur in the future: unfortunately in this work it is not always possible to achieve everything which we would wish to achieve, and often any achievements only take place over an extended period.'

17 October: In October 2005, after Mr J had recently required police assistance to return home

after becoming confused and anxious in public without support, various further assessments of Mr J's needs and abilities were carried out. An initial assessment was carried out by an occupational therapist (OT) in response to concern about Mr J's use of stairs. The OT recommended ground floor accommodation.

25 October: Mr J had a multidisciplinary assessment, which had to be abandoned because of Mr J's difficulty and distress with carrying out the tasks. It was noted that Mr J was showing signs of a decline in cognitive and adaptive skills, with an increase in ritualistic behaviour which would have a major impact on his care needs – his care package needed to be reviewed and updated.

October: Social services agreed to fund 21 hours support a week for Mr J (and the same for his wife).

2 November: Mr J's GP made an urgent referral to the NHS Trust because of concern about a marked general decline in Mr J's condition; he noted a recent history of falls and brief spasms suggesting epilepsy.

9 November: Social services assessed Mr J again.

11 November: Mr J was seen by a Consultant Psychiatrist (Dr A) whose initial assessment was that Mr J was suffering from depression and prescribed medication. However, she noted that there might be other underlying causes for Mr J's deterioration. Accordingly a nurse from the community learning disability team (CLDT) was asked to visit Mr J at home, and Dr A referred Mr J for a CT scan and an EEG. She also requested an application form for rehousing. It was noted that Mr J's brother was being kept up-to-date and was in full agreement with the current action being taken with regard to Mr J. (Mr K strongly disputes that he knew anything about these events.)

14 November: Dr A wrote to the GP. She noted that Mr J had regular contact with Mr K. Concerns about a change in Mr J's behaviour and a deterioration in his condition were noted, including that Mr J's wife had reported that he had fallen down several times. It was noted that at the appointment Mr J '*looked the picture of misery*'. He could not give any account of himself and had marked psychomotor retardation. She also noted that as Mr J's wife did not attend the appointment, she had had to rely on what Mr J's carers could report. Dr A asked to see Mr J with his wife in two weeks, detailed the medication she had prescribed, and said that she would arrange an EEG as soon as possible. If there were urgent concerns, an earlier appointment could be arranged. Dr A copied her letter to the Coquet Trust, the CLDT nurse and Mr J's social worker.

16 November: Mr J was seen again with his wife by Dr A. She recorded that Mr J and his wife had, after lengthy discussion, agreed to admission to Northgate Hospital as an informal patient for a five to six week assessment. (Dr A later wrote to the GP that the CLDT nurse had been very concerned about Mr J after visiting him and his wife at home; at the 16 November appointment Mrs N had become distraught and had been aggressive towards Mr J. Mr J had been upset and wept for about two hours. After discussion, his wife had agreed that it was in Mr J's best interests to be admitted for further assessment. Mr J had also agreed and was admitted.) There was no record of any assessment of Mr J's capacity to consent to admission being carried out.

17 November: Dr A wrote to the local acute hospital saying that Mr J had presented with a possible chronic subdural haematoma.¹⁶ She requested a CT scan and listed Mr J's symptoms.

19 November: Dr A telephoned Northgate Hospital to tell them that she had had the initial

results of Mr J's CT scan. This showed that there had been some changes, but did not indicate any urgent problem. She would therefore wait for the full results.

22 November: A service user's form regarding consent to share information (about his health and treatment) was completed for Mr J, saying that he did not have the capacity to consent and did not understand the implications of sharing information. (Several similar forms saying the same thing were completed over subsequent months, although there is no record of a formal assessment of Mr J's capacity being undertaken.)

1 December: A CPA meeting was held with Mr K present. Mr J's social worker was unable to attend due to sickness. At the meeting Dr A told Mr K that she had discontinued Mr J's antidepressant medication in order to be able to carry out baseline assessments of his blood pressure, mental state, and fit frequency. Dr A told the meeting that Mr J had cognitive decline and that it was proposed that Mr J's care should be transferred to another consultant psychiatrist, Dr B. The nursing reports prepared for this and subsequent CPA meetings all recorded that Mr J said that he wished to be discharged to live with his wife as soon as possible.

7 December: Mr J was referred to a speech and language therapist (SALT).

19 December: Mr K discussed Mr J's condition with Dr B on the telephone.

23 December: A different social worker called the NHS Trust to say that he would be Mr J's social worker from then onwards and that he would

arrange a meeting with Mr J's family as soon as possible.

29 December: Mr K raised a range of concerns with NHS Trust staff about Mr J's care and treatment on the ward, including the decision to put Mr J on a soft diet (he considered it to be unnecessary); Mr J's restricted lifestyle and lack of activity, which he believed was exacerbating Mr J's decline and depression (*'the ward was like a prison'*); and that there was a lack of communication with Mr J's family. Mr K asked when Mr J would be discharged and expressed dissatisfaction with the way social services were dealing with promoting Mr J's best interests. He also complained about the decision to stop prescribing antidepressants. Mr K said that Dr B had not answered his questions about why she had not asked him for information before coming to a view about Mr J.

The hospital records show that these matters then continued to be raised with the staff over the telephone by Mr K and Mr J's other siblings, when they called to ask how Mr J was, or when visiting.

2006

6 January: The SALT again recommended that Mr J should have a soft moist diet at all times and be supervised when eating and drinking.

10 January: Mr J, Mrs N and the OT visited Mr J's home in order to carry out an assessment. The OT noted that not only was the flat on the first floor, reached via a 14-step stairway, but the interior was also uneven with stepped access into several rooms, which meant that there was a high risk of Mr J falling. The OT considered that it was too dangerous for Mr J to return there.

¹⁶ A collection of blood (haemorrhage) over the surface of the brain, commonly caused by trauma, but can be spontaneous. It often requires surgical intervention.

12 January: An evidently difficult CPA meeting (which Mr K was asked to leave) took place. Mr K was told that Mr J had dementia and epilepsy and would need 24-hour care in future, but could leave hospital as soon as social services could provide appropriate support. (Following this meeting, staff did not ask Mr J's family to attend further CPA meetings, but it was noted in the files that the family should be kept informed about what had been discussed and agreed.)

Following this meeting, and at Mr K's instigation, Mr J was subsequently assigned an advocate from the advocacy project Skills for People, who attended all the CPA meetings from 9 February onwards until she left the project at the end of May 2006.

At the same time, to reduce the impact on patient care on the ward, the NHS Trust introduced some telephone and visiting guidelines for Mr J's family, which included restricting the number of telephone calls to Mr J's ward to twice a day, and the family's time on the ward to two hours a day, but did say that the family could take Mr J off the ward for an unspecified amount of time when they wished.

16 January: A CPA meeting again confirmed that Mr J could be discharged with appropriate accommodation and support. It was noted that social services had lead responsibility for finding suitable accommodation for Mr J and his wife. Dr B advised that temporary accommodation was not in Mr J's best interests, as it would mean his having to move twice.

18 January: Dr B wrote to Mrs L in response to the concerns raised by the family.

30 January: Mr J's social worker made a note that Dr B had said '*Mr J must not go home – far too dangerous*'.

31 January: Your Choice Homes sent Mr J a medical form regarding his application for housing.

6 February: Mr J's wife and social worker visited him. The social worker discussed accommodation and noted that Mr J said that he wanted to leave hospital and live with Mrs N. The social worker later recorded speaking to Your Choice Homes about likely timescales and being told that the current waiting list meant that it was likely to be at least six months before a property would be identified.

9 February: A CPA review took place. It was decided that, because of the time that Mr J had already been in hospital and Dr B's view that a further lengthy stay in hospital would be detrimental to Mr J, an interim placement would be better than a lengthy wait for a permanent placement. Mr J's social worker indicated that a first floor flat at the care home would become available from 8 March.

10 February: Mr J attended his woodwork class accompanied by a Coquet Trust worker.

14 February: Coquet Trust staff helped Mr J to complete the housing medical priority form which he had been sent in January.

16 February: An OT visited the care home and recommended adaptations (grab rails in the bathroom and a shower chair) that needed to be made before Mr J and his wife could move in.

22 February: Your Choice Homes received Mr J's completed medical form.

23 February: A further CPA review took place. It was noted that Mr J needed verbal and physical prompts to dress and for daily living tasks. He had been incontinent and now needed prompts to use the toilet. He was tearful at times and wished to live with his wife as soon as possible.

Mr J and his wife subsequently visited the care home.

28 February: Coquet Trust staff took Mr J to his woodwork class.

3 March: Mr K made formal complaints against the NHS Trust, social services and the Coquet Trust. In respect of the Coquet Trust, Mr K complained that the Coquet Trust had failed to communicate adequately with him about Mr J's situation, and that it had failed to press social services to fund more support for Mr J. He also complained that the support provided for Mr J had been inadequate, both prior to and during Mr J's admission to hospital.

In his complaint to the Council, Mr K complained that:

- Social services' support for Mr J had been inadequate and negligent since 2003, and that had contributed to Mr J's general decline.
- No one from social services had attended the CPA meeting on 1 December 2005.
- Social services had not communicated with Mr J's family.
- He had asked for details of Mr J's support packages since 1989, but had been informed by the social worker that it was unlikely those records still existed.
- Contrary to what had been promised, he had not heard from the learning disability manager since a meeting they had had on 25 January 2006.

In his complaint to the NHS Trust, Mr K complained about Mr J's admission to hospital, the diagnosis that had been made and about a number of different aspects of the care and treatment provided to him.

27 March: The Coquet Trust's general manager responded to Mr K's complaint saying that the Coquet Trust had always tried to work together with Mr J's family to get the best outcome for Mr J. It had asked social services to reassess Mr J, as it had considered that he would benefit from more support. Mr J had been reassessed and the hours increased, but shortly after this he had become poorly and had been admitted to hospital for assessment.

The general manager went on to say that, following further assessment, it had been decided that it would be unsafe for Mr J to return home and the Coquet Trust had then been asked to provide Mr J and his wife with a substantially increased level of support. It was hoped that, in the long term, suitable accommodation would be found but vacant properties were hard to find. In the meantime, temporary accommodation (at the care home) owned by the Council had been found. The flat '*would be very similar to living in their own house in the community*': a positive outcome enabling Mr J to live with his wife and have contact with staff who knew him well, with some additional staff, which would allow him to maintain his health, well-being and independence.

The Coquet Trust said that, following the OT home visit, it could not agree to continue as the support provider if Mr J moved back into his old home because it was unsafe. Mr K's concerns about a move for Mr J were noted; however, the assessment was correct, and Mr J would benefit from additional support hours and ground floor accommodation.

(The Coquet Trust did not take any further action in relation to Mr K's continuing dissatisfaction, because this went onto be dealt with under the Council's Stage 2 complaint and Stage 3 procedures.)

10 April: The learning disability manager responded on behalf of social services to the Stage 1 complaint. She said that a representative from social services had not attended the CPA meeting due to staff sickness. As regards communication failures, the learning disability manager said that following her meeting with Mr K, she had asked the staff involved with Mr J to keep Mr K informed. She apologised if Mr K felt that he was still not receiving important information and felt unable to communicate with Mr J's social worker, but added that his request that Mr J's social worker be removed could not be agreed, especially given the need to secure a discharge. The situation would be reviewed once Mr J was back in the community.

The learning disability manager said that she did not agree that Coquet Trust staff had neglected Mr J and his wife, but acknowledged that a more robust review system should have been in place. However, she pointed out that that would not necessarily have resulted in increased care hours. Due to the change in Mr J's circumstances, it had been necessary to seek different activities for him, which had coincided with Mr J's admission to hospital.

The learning disability manager said that a return to Mr J's home would have been preferred, but that that would be unsafe. A temporary move had been the only option available to secure Mr J's discharge from hospital. Social services were still looking for permanent accommodation in the same area as his old home; they were in contact with housing associations, private landlords and the Council's housing department.

Finally, she apologised for her failure to respond to Mr K following their meeting; she had mistakenly believed that other staff would be in communication with him.

12 April: The NHS Trust responded to Mr K's complaint. The chief executive summarised the background to Mr J's admission and Dr A's reasons for admitting him. He explained that the NHS Trust's medical director had spoken to Dr A and had examined the case notes and supported Dr A's decision.

The chief executive apologised, however, for not telling Mr J's family about his situation prior to admission, this had not been possible because of the specific circumstances and the urgency. He also apologised if Mr K felt that he and the rest of Mr J's family had been ignored, and more specifically for, not discussing issues relating to Mr J's condition prior to the meeting of 1 December 2005; if Mr K felt that the conversation with Dr B on 19 December 2005 had been unhelpful; and if staff had been unable fully to explain Mr J's EEG results. It was acknowledged that the CPA meeting held on 12 January 2006 had been difficult for all concerned.

The chief executive went on to say that Northgate Hospital was a renowned specialist hospital, expert in issues relating to Down's syndrome. Mr J's previous assessments by psychology staff from 1999 onwards were noted. He summarised the clinical reasoning behind the assessments and treatment plans including the decision to place Mr J on a soft diet. He agreed that Mr J would benefit from more exercise, but said that this was difficult to achieve given limited staff resources, efforts to arrange more exercise outside the ward area would continue. He also detailed the OT assessments and the relevant concerns regarding Mr J's mobility, perception and safety on stairs.

The chief executive concluded that the NHS Trust was anxious to discharge Mr J to a suitable environment. Possible temporary accommodation had been identified which Mr J and his wife had visited and were happy with. A CPA meeting had

been arranged for 18 May 2006 and it was hoped that Mr J would be discharged shortly after this. Hospital staff would remain in contact with Mr K and inform him of progress regarding discharge.

3 May: A note was made in the NHS Trust's records saying that the following lessons had been taken from Mr K's complaint.

- In some situations a meeting with the family might be indicated before formal review/CPA, and local ward procedures were to be reviewed in this respect;
- liaison between wards and community nurses in Newcastle needed to be improved;
- admission procedures should be reviewed to ensure appropriate contact with the local CLDT.

15 May: The NHS Trust's physiotherapist carried out a further assessment and found that Mr J's balance and mobility had deteriorated significantly over the preceding few months and that he now had a very high risk of falling. She recommended that Mr J should use a wheelchair for all outdoor activities, and that he should be accompanied when *'moving from one environment to another'* such as from outside to inside a building. At *'high risk'* times of the day, such as first thing in the morning, or when staff felt that he was unsteady, his wheelchair should be used. The OT found that although Mr J's physical abilities were fluctuating daily, he would ultimately need full use of a wheelchair and a mobile hoist in the bedroom.

18 May: In response to Mr K's objections to the proposals for Mr J's future accommodation, Mr J's advocate had referred the matter to the independent mental capacity service (a service established under new arrangements brought in under the *Mental Capacity Act*, which were the responsibility of local authorities); and Mr J had been allocated an independent mental

capacity advocate (IMCA). The IMCA had been asked to consider Mr J's best interests in respect of his accommodation, and ascertain if his own wishes, feelings and rights had been considered in the decisions regarding his discharge from hospital. In her report (dated 18 May) the IMCA noted that, although, given his diagnosis, Mr J's condition was unlikely to improve, and he would no longer be able to go out independently, he was not benefiting from being in hospital, separated from his wife and unable to lead a life that included enjoying some of his interests in a familiar environment with support staff that he knew. The IMCA agreed that Mr J would be at risk if he returned to his old home, however, she considered that Mr J should be discharged as soon as possible to temporary accommodation, as this would enable him to live with his wife. The IMCA said that it was important that the search for a local downstairs flat for Mr J and his wife should continue, and she passed on the name of a landlord. She recommended that the search for accommodation should include this possibility, as well as housing association and shared ownership accommodation.

The IMCA attended the CPA meeting that same day.

12 June: Mr J moved to the care home with his wife. (The Council decided to keep the couple's tenancy of their former home due to Mr J's deteriorating health and the need to ensure that Mrs N retained her rights to the tenancy.)

13 June: Social services wrote to Mr K to tell him that Mr J had moved. (Mr K subsequently complained that he did not receive the letter for a week.)

3 July: The action plan for Mr J's support in the care home required that the carers support Mr J in

telephoning his family each day, at a time suitable to Mr J.

13 July: Mr K complained to the Healthcare Commission.

20 July: The Coquet Trust wrote to Your Choice Homes asking for Mr J's medical priority to be reinstated. They thought that he had lost his priority status on 3 July 2006 because he had not previously bid for properties. Your Choice Homes was told that Mr J had been unable to bid because he had been ill and in hospital; the Coquet Trust added that he was now in temporary accommodation but that his need for ground-floor two-bedroom accommodation remained urgent.

The Coquet Trust wrote on the same day to the local authority's Supporting People officer to enquire about the possibility of a Supporting People contract for Mr J, including his wife. (There is no evidence of a reply being sent, or that that matter was followed up by the Coquet Trust.)

21 July: Dr B wrote to the GP, having carried out a review of Mr J at the care home. She considered that he had settled in well and that 24-hour support appeared to be working. She said that Mr J was still able to join in activities in the community, such as swimming, and he was still able to walk within the care home's grounds, but otherwise needed a wheelchair outdoors. No further myoclonic jerks had been recorded. On the whole he slept well. He had lost some weight since his discharge, but was still a healthy weight. He was occasionally doubly incontinent at night.

Dr B noted Mr K's request that Mr J and his wife stay with him for a few days. She advised that any major changes to Mr J's then current daily routine would significantly affect his functioning and emotional well-being. Whereas in the past a holiday might have been a stimulating and positive

experience, she believed that an overnight stay was now likely to cause him undue stress.

27 July: Mr K asked social services for a Stage 2 investigation of his complaint.

August: The Healthcare Commission considered that local resolution had not been completed and that another attempt should be made locally to resolve the NHS aspects of the complaint.

4 August: Mr J's social worker wrote to Mr K about his daily contact telephone call with Mr J. He said that the Coquet Trust support staff were concerned that the daily calls they made to the family (which were intended both to support Mr J's contact with his family and to update them on Mr J's well-being in the previous 24 hours) often lasted up to an hour, but were in the main not spent with the family talking to Mr J or Mrs N, but with the family making complaints to the staff about past and present support arrangements. That took staff away from caring for Mr J. He asked that any such complaints should be addressed to him, or to the Coquet Trust management. He also referred to Mr K's request that Mr J should ring at a set time each day, saying that there had to be some flexibility around the arrangements to suit Mr J's needs.

8 August: Mr J's medical priority for housing was reinstated.

19 August: Mr K set out the issues (some of which were new) that he wanted to be considered at a local resolution meeting with the NHS Trust.

25 August: The social worker informed Mr K that the medical advice from Dr B was that Mr K's request for a few days' visit should not go ahead.

11 October: Mr K attended a local resolution meeting with the NHS Trust; a senior social

services manager also attended. At the meeting the following action plans were agreed:

- It was acknowledged that communication with the family had been inadequate and this was apologised for. Future communication with Mr J's family would be improved.
- A social services team leader would visit Mr J to carry out a formal care plan review, which would include activities. The review would involve all those who provided support to Mr J. A strategy for facilitating communication between all the various parties would also be developed.
- Mr J's consultant would be changed and a second opinion would be obtained regarding Mr J's mobility and diet.
- Regarding the care home, the meeting noted that the IMCA advocate's report had supported Mr J's move. This was not ideal but social services were actively pursuing permanent housing. A second opinion on Mr J's mobility might prove helpful.
- The meeting noted that Mr K had been unaware of previous referrals by the GP and the Coquet Trust to the CLDT, and the involvement of the community nurse and psychologist, until Mr J's admission in November 2005. It was noted that correspondence had been sent to Mr J's wife, and it had been assumed that the Coquet Trust support workers would have explained its meaning to her. It was also noted that Mr K would take practical steps towards becoming Mr J's legal guardian.
- It was agreed that monitoring of weight should be carried out in a consistent way, that is, in the same clothes, using the same scales.

18 October: Another consultant psychiatrist took over Mr J's care.

Mr J's condition continued to decline, and his family continued to express their dissatisfaction with the care and support being provided to Mr J. Mr J's records indicate that Mr J was often tearful at this time, and that his wife was finding it difficult to cope. Mr K also complained about the difficulty the family were having trying to communicate with Mr J because the flat at the care home did not have a landline telephone. He said that, although Mr J had been given a mobile phone, this was expensive and Mr J had difficulty with it.

27 October: Your Choice Homes offered a property for consideration for Mr J and Mrs N. The flat was visited by Mr J's social worker, the community nurse, the physiotherapist, the occupational therapist, two housing association representatives and two staff from the Coquet Trust to assess whether it was suitable. They decided that the bedrooms were too small to enable staff to be able to meet Mr J's care needs (including the use of a bed hoist when required), and the offer was therefore refused. Neither Mr J nor Mr K were told about this offer.

2 November: Another offer of accommodation was made.

9 November: The NHS Trust wrote to Mr K following the local resolution meeting on 11 October to summarise the main points from the meeting and to note agreed action items (as set out in the above entry). The letter acknowledged that Mr J's relatives had always been, and continued to be, involved as carers in supporting Mr J. The response noted that Mr K's complaint to social services was currently being processed. The NHS Trust again apologised for shortcomings in communication and for the fact that Mr K had not been informed about the referrals by Mr J's GP and the Coquet Trust to Dr A until after Mr J had been admitted to hospital. It explained that the CLDT had had to take action and that information

and relevant correspondence had been sent to Mr J's wife, who was his next of kin. It had been assumed that the Coquet Trust would explain to her the content of the correspondence. The NHS Trust would strive to ensure that all future communications involving Trust staff, Mr J, his family and social services would be appropriately co-ordinated. It was noted that arrangements had been made for responsibility for Mr J's care to be transferred to another consultant. Regarding Mr J's discharge to the care home, it was noted that Mr K had commented that there had been insufficient consultation with the family before this had happened, and that the family's view was that Mr J should be supported to return to his and Mrs N's flat.

13 November: Mr J's medical priority for rehousing expired because no interest had been expressed in the properties offered.

30 November: The flat offered on 2 November was visited by Mr J's physiotherapist, who sent the community nurse and the OT a note saying that there were steps up to the front door, the corridors were narrow and that work would have to be done to convert the bathroom into a wet room and to widen the door to the bathroom. She asked for their views.

4 December: The community nurse and the OT discussed the second property offered and decided that it did not meet Mr J's needs and that '*alterations would take too long and that his condition may deteriorate before being able to make to house user friendly [sic]*'. The community nurse then advised the Coquet Trust to decline the property. Mr J and Mr K were, once again, not informed of this.

7 December: Mr J was admitted to hospital with a suspected chest infection and shortness of breath. He was discharged the following day as an X-ray showed his chest to be completely clear.

2007

8 January: Mr J and Mrs N returned from spending the Christmas period with Mr K and his wife.

24 January – 25 February: Mr J went to stay with Mr K and his wife.

3 April: The records hold no information about Mr J's health on this day.

4 April: Community nurses attended Mr J to dress a sore elbow. A GP also attended and found that, although there were some noises, his chest was clear. The doctor noted that the noises identified could be due to Mr J not swallowing food properly and regurgitating it. There was no record of Mr J having a dry cough or with phlegm, or presenting with flu-like symptoms. The next support staff entry in the records indicated that Mr J was having problems eating a full meal, but implied that this was an ongoing problem and not something new in the last few days.

5 April – 6 April: No further health problems were recorded for Mr J.

7 April: Mr J was noted to be very hot, to have shallow breathing, and to be limp and unable to bear weight. He was unable to take oral medication. The GP considered he should be taken to hospital and he was admitted around lunchtime.

9 April: Mr J died from pneumonia. (No post mortem was carried out.)

2008

January: The Council issued the report of the Stage 2 investigation (15 months after Mr K had asked social services for a Stage 2 review and nine months after Mr J's death). The report dealt with 24 heads of complaint. A brief summary of the report's findings follows.

The investigator (a designated complaints officer within the social services department) commented that he could not question Mr J's diagnosis. He noted that although it was clear that admission to hospital had been previously proposed, the admission on 16 November 2005 had been unplanned and urgent due to concerns about safety. He said that social services had not been involved in that decision; therefore he did not uphold the complaint that social services and the Coquet Trust had failed to inform Mr J's family that he was going into hospital.

The investigator was critical of social services' and the Coquet Trust's communication with Mr K for the period covered by the complaint. He was also critical of the care and support Mr J had received in the 12 months before his admission from both social services and the Coquet Trust, particularly the failure to resolve the request for more support for Mr J, including work-type activities. However, although communication between the Coquet Trust and social services prior to admission had been insufficient, there had been a significant improvement when Mr J moved to the care home, when there had been almost daily contact.

The following complaints were not upheld, that:

- Social services had not allowed Mr J to participate in decisions about his care.
- The Coquet Trust should have asked social services for more support.
- Social services and the Coquet Trust had failed to provide opportunities for Mr J to develop his daily living skills.
- Social services and the Coquet Trust had failed to ensure that Mr J's diet was nutritionally adequate.
- Social services and the Coquet Trust had failed to inform Mr J's family that he was going into hospital.

- Social services had not protected Mr J's right to liberty.
- Social services had failed to attend the CPA meeting held on 1 December 2005.
- Social services had failed to promote Mr J's independence during his stay in hospital.
- Social services had been insufficiently proactive regarding alternatives to hospital.
- Social services had failed to help Mr J to maintain daily living skills in hospital.
- Social services had excluded Mr K in matters relating to Mr J's care following his admission to hospital.
- The Coquet Trust had failed to bring Mr J's clothes to hospital.

The following complaints were partly upheld, that:

- Social services and the Coquet Trust had failed to inform the NHS about Mr J's family, and relevant family history.
- The Coquet Trust had failed to keep Mr J active during his stay in hospital.
- Social services had failed to keep Mr K fully informed about the details of Mr J's discharge from hospital and future care arrangements.

The following complaints were fully upheld, that:

- Social services had failed to keep Mr K informed about support prior to admission to hospital.
- Social services had left Mr J without support for four days a week.
- Social services had failed to help Mr J find alternate work placements.
- Social services had failed to contact Mr K regarding discharge plans.
- Social services had failed to contact Mr K to discuss Mr J's future and had wrongly

suggested that this was the responsibility of other agencies.

- The learning disability manager had failed to keep Mr K informed as agreed.

The investigator concluded that extra support would not have prevented Mr J's health deteriorating, but might have improved his quality of life and alleviated some of the pressures at home. He made the following recommendations:

- An apology from the Coquet Trust and social services for acting far too slowly to resolve the need for extra help.
- An apology from social services regarding: lack of communication by a social worker, a failure to pursue housing for Mr J and delay with the Stage 2 report.
- A written explanation from the Coquet Trust of why they did not find Mr J an alternative placement after 2003.
- The Coquet Trust to decide in what circumstances it would be appropriate to find an advocate for a service user.

23 January: The acting head of adult social care wrote telling Mr K that social services fully accepted the Stage 2 recommendations with the exception of one. He said that it would not usually be the care provider's responsibility to find work placements, even if there was some evidence to indicate that the Coquet Trust had accepted responsibility for this. He considered that this should have been made more evident in the review.

He apologised for the fact that a year had elapsed before the impact of Mr J's changing circumstances had been properly understood and responded to. However, he said, additional support had been agreed within ten days of the risk to Mr J being made clear. The Council accepted that social

services had had a responsibility to formulate a plan. He apologised that the social worker had failed to communicate with Mr J's family as he should have done, and also for the fact that alternative housing had not been pursued with sufficient urgency. He concluded by apologising for the fact that the complex nature of the complaint meant that the investigation had taken longer than expected.

5 March: Mr K remained dissatisfied and asked to go to Stage 3 of the social services complaints procedure.

2 April: The Stage 3 panel was held. The panel's role was to review the Stage 2 investigation and how the Council had sought to remedy the Stage 2 findings. The Panel concluded that the crux of the complaints was poor communication between the professionals and Mr J's family. Consequently, Mr K had felt excluded from decision making and unable to present alternative views.

The panel considered that on the whole the Stage 2 report had been thorough and balanced, albeit delayed. However, the panel did not consider that the response to the Stage 2 investigation went far enough. The panel concluded that the Council's response had addressed the Stage 2 recommendations, but not adequately the substance of the complaint. Its findings were as follows:

- (i) That social services had not protected Mr J's right to liberty, by uncritically accepting his admission and subsequent stay in hospital: the panel found that social services had been insufficiently proactive regarding Mr J's condition prior to the admission to contribute to the decision making process. The 'comprehensive' assessment of 9 November 2005 was largely a paper

exercise and requests for additional support had not been dealt with in a timely manner. After Mr J's admission they had been actively involved in trying to facilitate his discharge, as soon as it was safe to do so.

- (ii) The panel considered that after admission social services had acted as quickly as they could to facilitate discharge, and took all reasonable steps to find suitable accommodation, with the exception of not sufficiently exploring the option of Mr J staying temporarily with his brother. The Panel said that responsibility for maintaining skills lay with the NHS, during the stay in hospital. Likewise, issues relating to diet, not using the stairs and wheelchair provision, were matters for the NHS.
- (iii) The panel noted that Mr K's regular contact had been with the Coquet Trust. However, social services had a direct responsibility to provide relevant information, and communication with Mr J's family had been poor. The panel understood why Mr K had felt excluded; but did not consider that he had been excluded from all matters relating to Mr J's care; rather that social services had failed to facilitate the family's participation. Therefore, the panel did not accept the Stage 2 conclusions on this matter and considered that this aspect of the complaint should be partly upheld.

Regarding the complaint that social services and the Coquet Trust had failed to offer adequate opportunities for daily living skills, the panel did not agree with the Stage 2 conclusions. They accepted that social services had failed to respond to the Coquet Trust's requests for increased hours and that the latter had supported Mr J

appropriately within the limits of allocated hours. Following discharge, both social services and the Coquet Trust had supported Mr J appropriately.

The panel accepted that Mr J's admission for assessment had been unplanned but noted that plans had been in hand for a visit to prepare Mr J for admission later in the month. Mr J's family had not been informed of this, but as Mr K had already raised concerns with the Coquet Trust about Mr J's functioning, the panel concluded that the complaint should be partly upheld.

The panel agreed with the other Stage 2 conclusions and also found that Mr K had genuine reasons for concern about complaint handling including delay, a lack of face-to-face interviews, and poor presentation of documents.

The panel noted Mr K's new desired outcomes:

- Active involvement of families.
- Learning from his complaint.
- Addressing discrimination and the presumption of dementia.

The panel recommended that adult services should:

1. Provide awareness training for workers in services for adults with Down's syndrome.
2. Reinforce with social workers the importance of good communication with families.
3. Review individual decision-making, in the light of the *Mental Capacity Act* and legislation for the protection of vulnerable adults.
4. Share his complaint with inspectors at the next statutory inspection.
5. Comply with government guidance on complaints.

16 April: The CLDT meeting minutes for 16 April 2008 show that Mr J's case was discussed there. It was noted that the majority of the complaints concerned communication: 24 issues had been raised, of which 14 had been upheld wholly or in part. The importance of documenting information was noted. The minutes also state:

'... it is vital that social workers keep the family informed at every stage of developments. ... Team managers will continue to discuss issues of communication as part of supervision sessions and will continue to monitor all situations that give cause for concern.'

28 April: The Council responded to the Stage 3 findings. The director of adult services again apologised for the failure to communicate with the family. He said that an action plan was being developed. The Council would go beyond the recommendations, and better guidance and procedures would result, especially in regard to independent providers.

He acknowledged a failure to explore extra activities for Mr J with the Coquet Trust, but said that it was impossible to establish whether Mr J would have been able to maintain his skills had these been provided.

Referring to the *Mental Capacity Act*, and legislation for the protection of vulnerable adults, the Director noted that 2006 policies had now been superseded by new guidance and protocols, which were regularly reviewed and updated in line with legislation and government guidance. The service was committed to continuous improvement – therefore a specific review was not necessary.

The Council would implement the remaining recommendations and had been selected by the DH to test new ways of responding to complaints across health and social care over the next 12 months, which would lead to the identification of good practice. He offered to meet Mr K and informed him about the role of the Local Government Ombudsman.

July: Mr K's complaints against the NHS Trust, the Council and the Coquet Trust, which in March 2008 the Healthcare Commission had referred to the Health Service Ombudsman for consideration of a joint investigation with the Local Government Ombudsman, were accepted for joint investigation by both Ombudsmen.

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