MENTAL WELFARE COMMISSION
FOR SCOTLAND

REPORT OF THE INQUIRY INTO THE CARE AND TREATMENT OF MR C

OCTOBER 2002

Contents

Editorial Note

To preserve the anonymity of individuals and locations there has been some editing of data and other information which was included as supporting evidence in the unanonymised report available only to those who took part in the Inquiry. This editing does not affect the report's findings or argument.

SECTION 1:

Section 1.1 Brief Background

1.1.1 Mr C, who is now 86, is a widower with four sons. He was a baker until he retired aged 65; he then worked part-time as a barman. In October 1996 Mr C's wife died after a long illness; he had cared for her for a considerable time. He was a physically fit man with no history of psychiatric problems although at an unknown date he was registered blind because of macular degeneration of the retina. He used a white stick. Mr C used to manage his own finances, receiving a state pension and attendance allowance. Despite Mr C's limited vision he cared capably for himself, his wife and their house until her death. After this Mr C's short-term memory loss was noted and from April 1997 he received about forty-five minutes help, seven days a week from the home support service, and at the weekend he went to a Day Centre. He also received considerable help from his son and daughter-in-law who visited three or four times a day.

1.1.2 Mr C's short-term memory continued to deteriorate and in February 1998 he was referred to the Community Dementia Team for an urgent assessment. The notes record that his dementia is probably vascular. Following this assessment homecare services were enhanced and a community psychiatric nurse continued to visit Mr C. A few months later Mr C began to wander from his home causing his family considerable anxiety and distress. In July 1998 Social Work Services arranged a two week period of respite residential care. After Mr C returned home there were again incidences of nocturnal wandering and a further period of residential respite care was arranged in November 1998, in part to assess whether Mr C should move permanently to a care home.

1.1.3 During this second period of respite care Mr C became agitated and staff found his occasional aggressive behaviour too difficult to manage. He was therefore admitted to an acute psycho-geriatric admission ward in Prince Hospital. In March 1999 it was decided that Mr C should move from hospital to a nursing home which had a unit for elderly mentally infirm residents. The nursing home Mr C's family chose did not have a vacancy and in July 1999 Mr C was moved from the acute to a long- stay ward. Mr C remained in Prince Hospital in long-stay wards for a further two years and two months because there were either no funds for his nursing home placement or no vacancy in the chosen home. Mr C became seen as a "bed blocker". Because of hospital reorganisation, or the need to vacate a bed, Mr C experienced several changes of ward. For most of his stay in Prince Mr C lived in long-stay wards which had no regular occupational therapy and virtually no activities. There were difficulties in obtaining funds for his everyday needs. Mr C remained physically fit; he presented very little management problem and he spent his days walking up and down the wards' corridors. He was much more capable than any of his fellow patients.

1.1.4 The Mental Welfare Commission became aware of Mr C in November 2000 during the annual hospital visit to Prince Hospital. Visits are routinely made to wards where there have been no requests for visits and Mr C was identified as a patient who had been waiting for a nursing home bed for 610 days. Following enquiries the Commission was informed by Social Work Services that it was not possible to say

when Mr C could be admitted to a nursing home as the funding and placement had to match. After making further enquiries the Commission decided in June 2001 to carry out an Inquiry under Section 3(2)(a) of the Mental Health (Scotland) Act 1984. Mr C finally moved to a nursing home on 12 September 2001 after a hospital stay of nearly three years. He settled happily into the nursing home and continues to have a contented life there.

1.2 Terms of Reference

1.2.1 In June 2001 the Commission decided to carry out an Inquiry under Section 3(2)(a) of the Mental Health (Scotland) Act 1984 into the care and treatment of Mr C from his initial assessment for community care in October 1998 until his discharge from Prince Hospital in September 2001.

1.2.2 The Commission decided that the Inquiry should focus on the following matters:

(i) The assessments made of Mr C's needs

(ii) Arrangements for the review of these needs

(iii) Mr C's care and treatment

(iv) Decisions regarding community care arrangements and the contribution to these decisions of relatives, local authority, medical and nursing staff and the patient

(v) Mechanisms for allocating priority for people assessed as requiring community care

(vi) Mechanisms for ensuring that funding is available when a suitable placement is secured

(vii) Arrangements for resource transfer in Yshire Primary Care Trust

(viii) The contribution of the Yshire reorganisation of community health and social work services to resolving identified problems

1.3 Inquiry Team

- Professor Juliet Cheetham, Social Work Commissioner, Chair of the Inquiry
- Mr Malcolm Murray, Part-time Commissioner
- Ms Margaret Anne Gilbert, Social Work Officer

The Team was assisted by Mrs Yvonne Osman and Ms Gail McKenzie from the Commission's Inquiries and Investigation Unit.

1.4 Methods undertaken by the Inquiry

1.4.1 The Inquiry's investigation began with the assembling and perusal of the medical, nursing and social work records. Further written materials such as protocols and guidance notes were also reviewed.

1.4.2 Mr C was visited in the nursing home to which he had moved two months after the inquiry began. Visits were also paid to some of the wards in which Mr C had been a patient in Prince Hospital.

1.4.3 The list of people interviewed by the Inquiry Team is given at paragraph 1.5. These interviews took place at Prince Hospital and in the Commission offices. All those approached by the Inquiry Team co-operated fully and provided a substantial amount of information. Notes were taken at the interviews which were also tape recorded. A record of each interview was sent to the persons concerned to be corrected for factual accuracy.

1.4.4 It was made clear to all those interviewed that the Commission would make a report of the Inquiry to the relevant bodies according to the terms of the Mental Health (Scotland) Act 1984.

1.5 List of Persons Interviewed

(Those who had some direct responsibility for Mr C are marked with an asterisk. The posts indicated are those they held at that time).

Medical Staff:

*Dr A, Consultant Psychiatrist, Prince Hospital
*Dr B, Specialist Registrar, Prince Hospital
*Dr C, Consultant Psychiatrist, Prince Hospital
*Dr D, Consultant Psychiatrist, Prince Hospital

Nursing Staff:

*Mr E, Community Psychiatric Nurse
*Ms G, Named Nurse
*Mr F, Senior Charge Nurse
*Mr G, Named Nurse
*Ms H, Senior Charge Nurse
*Ms I, Senior Charge Nurse
*Mr J, Ward Manager

Social Work Staff:

Mr M, Head of Service, Yshire Council Social Work Department
Mr L, Senior Operations Manager
*Mr N, Service Manager, Yshire Council Social Work Department
*Ms O, Care Manager, Yshire Council Social Work Department

Trust, Hospital and Local Authority Management:

Mr P, Old Age Psychiatry Speciality Manager
Mr Q, Finance Director, Yshire Primary Care NHS Trust
Mr R, Service Manager (Finance) Yshire Council
*Ms S, Hospital Cashier/Patients' Funds Officer

Other Services:

Ms T, Head of Occupational Therapy
Ms U, Superintendent Physiotherapist

Mr C's Family:

Mr C junior (son)

SECTION 2:

Section 2.1 Statement of Fact

2.1.1 Following continuing concerns about Mr C's deteriorating memory and reduced ability to care for himself Mr E, his Community Psychiatric Nurse, referred him on 13 October 1998 to Yshire Social Work Services for an assessment of need. Mr C had recently had a week's respite care in a residential home to allow his son to go on holiday. The assessment was carried out by Mr Y, Care Manager, on 29 October 1998. There was no assessment by an occupational therapist. Mr Y recorded that Mr C had little insight into his needs and was having problems feeding and dressing himself. He had stopped attending the day centre. His son, Mr C junior, visited his father three or four times a day to ensure, amongst other things, he was eating properly. Mr C Junior was said to be deeply concerned about his father's safety at home because he was not using gas appliances properly. The Inquiry Team were also told that Mr C Senior would touch the cooker burners to see if they were on. In addition, Mr C Senior was regularly leaving home very early in the morning, perhaps following the pattern established when he was a baker and would rise at 4.00 am. He was frequently getting lost and we were told that on one occasion Mr C Senior checked himself into a hotel believing he was in another town. He was lost for some time and there was a full-scale police search. Overnight supervision was thought to be necessary but not available. Mr C Junior was reported as being very stressed. The assessment report concluded that Mr C should have a three week period of respite care during which the possibility of permanent care would be considered.

2.1.2 Mr C Junior told us that he had been happy to help his father, with whom he had a deep bond, but the strain of caring for him, without much outside help was considerable and had an adverse effect on his family. He therefore accepted Mr E's advice that it had at that point become too difficult for him to provide all the care his father needed. Mr C Junior was not offered an assessment of his needs as a carer.

2.1.3 Mr C Senior was admitted to East House, a local authority residential home, for this respite care on 1 November 1998. The placement was reviewed after two weeks and extended for a further month. Mr C did not settle well. He wandered into other residents' rooms at night and sometimes attempted to get into their beds which was reported as putting residents "into a state of alarm".

2.1.4 At the next review on 10 December 1998 Mr C was described as being much more confused and irritable with very disturbed sleep patterns. He was not accepting help with personal care and was on occasions being aggressive with staff. The medication which had been prescribed (Temazepam 10 mg nocte (at night) and Thioridazine 2.5 mg TID) had not had a significant effect. A stay in hospital for psychiatric assessment was thought appropriate.

2.1.5 The Inquiry Team were unable to interview Mr Y about this period of care because of his long term sickness. However, Mr E, who remained Mr C's CPN during this period, was able to provide more information than was available in the written records.

2.1.6 Mr E had observed in his notes that Mr C's behaviour could be connected with his limited awareness of a new environment and his poor vision. He had noticed some decline in Mr C's cognition and functioning. He also noted that the staff were finding it increasingly difficult to cope and that at least one member of staff had received some bruising to her arm. The review on 10 December 1998 involving Mr Y, Mr E, staff of East House and Mr C Junior and his wife records a significant increase in confusion and irritability, very disturbed sleep patterns and reluctance to accept help with personal care. A psychiatric assessment was therefore requested. Dr C, Consultant at Prince Hospital and Mr E met Mr C Senior on 15 December 1998 and after this assessment in East House, Mr C was admitted to Short Ward in Prince Hospital on 19 December 1998.

2.1.7 Mr E told us that Mr C Junior had initially been reluctant for his father to go into Prince Hospital. However, he was aware that staff in East House had become very concerned about their ability to care for him and if he returned to his own home he would need 24 hour care. It would not be possible for Mr C Junior to provide this; he had already given a great deal of time to his father and he also had domestic commitments and employment with unsocial hours in a department store. There is no record of a carer's assessment being offered to Mr C Junior but some references in the social work note that he was "stressed" and "struggling to cope".

Assessment Admission to Short Ward, 9 December 1998 - 5 July 1999

2.1.8 On admission to Short Ward the medical and nursing notes record a diagnosis of vascular dementia and behavioural problems, including urinary incontinence. Thioridazine 25 mg once per day and PRN was prescribed. On the Mini-Mental State Examination Mr C's score in March 1998 was 21/30. In December 1998, while he was in East House, his score was 12/30. When admitted to Short Ward later that month his score was again recorded as 21/30; by March 1999 Mr C's score was 14/30. We are aware that some items in this examination can be affected by the way a person's blindness is dealt with and by the degree of stimulation to which they were exposed before testing. There appears to have been no discussion of these fluctuations which could have had implications for Mr C's care planning.

2.1.9 The nursing notes record that Mr C communicated well with staff and, although registered blind, this did not appear to be a problem for him or his care. He could walk unaided and did not use his cane. He could wash and dress himself but needed bathing assistance; he had good mobility, ate well and was fully continent during the day, although occasionally incontinent of urine at night. He mostly slept well and was not a danger to himself or others although he could be aggressive and restless in the early evening. He was not depressed, elated or deluded. His long-term memory was good but his short-term memory was impaired; he lacked insight because of his mental state. He was orientated for person, but disorientated for place and occasionally for time. He paced up and down the corridor aimlessly. He was referred to occupational therapy.

2.1.10 This pattern of behaviour continued throughout Mr C's stay in Short Ward. A few instances of mild aggression were recorded and on one or two occasions Mr C was said to make sexually inappropriate remarks to other patients. There were continuing

problems with urinary incontinence. Mr C was frequently described as pleasant and humorous and quite easy to settle when he became restless. His medication was changed to Thioridazine 25 mg TID and 50 mg nocte and on 21 January it is noted that he had settled on this medication. However, because of some continuing irritability Clopixol 6mgs was prescribed on 15 February 1999 and a review of his future care delayed to assess his response. Mr C was also treated for some skin infection which caused anxiety because MRSA was at that time present in the ward. As a consequence he was moved from a dormitory bed to a side ward.

2.1.11 After Mr C's occupational therapy assessment on 6 January 1999, which noted his several capabilities as well as his confusion and short-term memory problem, he attended Short Ward's daily occupational therapy groups for reality orientation and reminiscence. The notes also stated that if Mr C was to return home there would be a full range of functional assessments. At that time an occupational therapist attended the weekly multidisciplinary ward meetings. On 24 June 1999, after it had been agreed that Mr C should go to a nursing home and, to await this place, to a continuing care ward, the occupational therapy notes record Mr C as being "not suitable for OT – no active input required". We were not able to obtain further information about this decision. There is no record of any contribution from an occupational therapist to the decision about Mr C's future care.

2.1.12 Mr C also attended daily physiotherapy groups which included music and movement and games. Although initially he had been bright and alert Ms U, superintendent physiotherapist told us he was discharged from the group on 23 June 1999 because he had become agitated and restless and had disturbed the class.

2.1.13 On 5 January 1999 the nursing notes record that Mr C was visited by a solicitor and that his signature was obtained for a Power of Attorney in favour of his son. The notes record that the solicitor would be writing to Dr C and that this matter was to be discussed with Dr C. On 14 January 1999 the medical notes record "Dr C wondered whether Dr B could contact solicitor. It is now felt that as solicitor will be writing to Dr C we shall await this correspondence.". Mr C Junior told us that he had been advised that a Power of Attorney could be useful. Mr E told us he had given this advice. Neither Mr C Junior's own nor his father's solicitor was involved. Mr C Junior said he could not recall exactly how the solicitor had been found but it might have been through the hospital.

2.1.14 There is no record of any correspondence about this matter in any of Mr C's files. Dr B confirmed with the Inquiry Team that it had been agreed at a ward round that further enquiries should not be made until the solicitor contacted Dr C. Dr C told us that because there was no contact from the solicitor it was assumed that nothing had happened. However, Mr C had in fact signed, in a very shaky hand, a Power of Attorney in favour of his son on 5 January 1999 the day the solicitor visited him. Mr C's capacity was not assessed while he was in Short Ward. We were told this was common practice for patients in acute wards who were not expected to stay there long. Declarations that a patient was Incapax would usually only be made for people on continuing care wards.

2.1.15 Whilst Mr C was in Short Ward there were weekly ward round entries in his medical notes. There were also full nursing care plans. Apart from the note of the review of Mr C's care plan on 25 March 1999 there is no note in the social work records of any contact with Mr C Senior or Junior during this period. Because of Mr Y's absence on long term sick leave we were not able to obtain further information on this point. Mr C Junior told us that after his father's admission to hospital he had very little contact with a social worker.

2.1.16 During Mr C's stay in Short Ward it is not clear how often he was visited by his son. There are records of four such visits in the nursing notes, including an outing on Christmas Day to Mr C Junior's home. However, Mr K, Charge Nurse for Short Ward told us there had been quite frequent visits from Mr C Junior. Mr C Junior also told us that he had visited his father quite often.

2.1.17 At the multi-disciplinary review of Mr C's current care plan on 25 March 1999 the social work note records that Mr C's mental health had now stabilised and that there had been a multidisciplinary decision that his needs could be met in a nursing home with an EMI (Elderly Mentally Infirm) unit. He would therefore be transferred to a long-stay ward until funding could be approved. Mr C Junior would visit nursing homes in Ytown to identify his preferred placement for his father and Mr Y would submit a request for funding. This note records the presence of Dr C, Mr Y, nursing staff and Mr C Junior. There is no account of the matters which had been considered in reaching this decision or of consideration of any alternatives. Mr C Junior told us that he then visited several homes, some of which did not have appropriate resources for his father. He had no hesitation in selecting Hilltop Nursing Home which, in his opinion, compared with others he visited, "seemed like the Hilton of homes".

2.1.18 Mr C was placed on the waiting list of Hilltop in May 1999. Since no further hospital assessment was required it was agreed Mr C would be moved to West Ward in July 1999. From this time there are frequent references in the notes to Mr C being "a bed blocker" which one consultant remarked was "an awful term".

Mr C's stay in West Ward 5 July 1999 to 4 September 1999

2.1.19 Mr C was transferred to West Ward on 5 July 1999. The physical layout of West Ward was identical to that of Short with a long corridor, dormitories and side rooms. West, like other continuing care wards which Mr C was to occupy for the next two years, provided a very different environment to Short Ward. Continuing care wards are intended for people who need long term care provided by the National Health Service. We were told by Mr C's named nurses that going from an assessment to a continuing care ward would be "a sharp drop". Mr C was the only person in West Ward who was awaiting a nursing home placement. He was also the only ambulant patient and the only one who could conduct a conversation. Although most patients in the ward could not have taken part in regular occupational therapy or physiotherapy classes, nurses thought Mr C could have done this. However, the continuing care wards were differently resourced with no routine social work, occupational therapy or physiotherapy unless a specific referral was made for an individual patient. Ward managers told us they had made repeated but unsuccessful requests to these services to be regularly available on continuing care wards. We

were also told that multidisciplinary reviews would be attended only by the consultant and the named nurse.

2.1.20 There are no organised activities for patients on continuing care wards and we were told in graphic terms by the ward managers and named nurses how difficult it was to provide even a basic quality of life for patients. Staff resources were limited with four to five nurses being required but frequently only three or four being available. Four nurses were regarded as the minimum number required for safety. Basic care – getting people up, bathed, toileted, dressed and fed - was the realistic goal. It was not possible to organise outings or even to take patients out of the ward in the summer. Nurses had, however, made efforts to occupy Mr C and to engage him in conversation about football and his other interests. He was described as a witty, jovial, happy go lucky and very pleasant gentleman, "a character". Because of his personality and his ability to communicate Mr C received quite a lot of individual attention from nursing and domestic staff. They enjoyed his company.

2.1.21 The nursing notes record that Mr C was under the consultant care of Dr D but Dr D told us that he was only briefly responsible for Mr C when he was in South Ward for a few months early in 2000.

2.1.22 The medical notes for Mr C's stay in West Ward are very brief, consisting of just two entries. These record Mr C as co-operative except for bathing, fully ambulant, incontinent at night and as having had two falls.

2.1.23 The nursing notes describe Mr C as pleasant, polite and co-operative. Although there are frequent references to urinary incontinence and a few falls, Mr C was not regarded as presenting management problems. His blindness was also seen as presenting no difficulties. Mr C's nursing care plan refers to the need to maintain a safe environment because of his tendency to fall.

2.1.24 In July 1999 it is noted that Mr C required toiletries and clothing. His son was contacted about this and said he would supply what was necessary. However, Mr V, Mr C's named nurse, said that Mr C Junior did not visit the ward for two or three months and did not respond to requests for what his father needed. Mr V said there were no strained relationships with Mr C Junior; however, over time he simply visited the ward less and less. Mr C Junior told us he regularly provided items his father needed.

2.1.25 The social work note for this period records some administrative matters. In August 1999 it was agreed Mr C would have a new care manager and in September 1999 Ms O took over this role. Mr V told us that he had contact with Social Work Services once or twice because of problems with Mr C's finances and his need for clothing and the difficulties of obtaining these articles because his son was not visiting. Mr V also said that he had been told by Mr C's care manager that he was a long way down the waiting list for Hilltop Nursing Home.

4 September 1999 – Transfer to East Ward (merged with South Ward March 2000)

2.1.26 Mr C was transferred to East Ward in September 1999 as part of what the Trust described as "site rationalisation precipitating a reduction in long-stay bed numbers". This arrangement was intended as an interim measure until it was possible to transfer patients into the adjacent and modified South Ward as the final stage of the site rationalisation programme. These changes were part of the Trust strategic plan to reduce the number of beds for people with dementia in Prince Hospital and open additional dementia wards in other localities. The staff of West Ward moved with Mr C to East Ward. We were also told that a large number of the staff then moved to South Ward so preserving some continuity of care for Mr C.

2.1.27 The nursing notes record Dr D as Mr C's consultant until January 2000 when Dr C assumed this responsibility.

2.1.28 The medical notes during Mr C's stay in East Ward continue to record no management problems. Mr C's Clopixol medication was reduced from 6 mg to 2 mg daily. This was later recorded as having good effect. A long-stay summary dated 29 September 1999 describes Mr C as "an 84 year old gentleman admitted to East Ward for transitional care. No major management problem; mobility independent since Clopixol reduced; feeds himself; drinks well; mobile in spite of blindness; occasional independent toileting but doubly incontinent most of the time. Able to communicate with occasional meaningful conversation; co-operative except when bathed; very seldom gets restless; no evidence of psychotic symptomatology; not Incapax".

2.1.29 There are no medical notes from 26 October 1999 to 15 February 2001. We were told by Dr C, who was responsible for Mr C's care from 1 January 2000 to 1 January 2001, that during this period Mr C's day to day clinical management was undertaken by a general practitioner clinical assistant who attended to all physical care needs of patients in South and East Wards. Medical notes under these circumstances were usually hand written and the Trust had been unable to locate these notes. Type written notes would only be made in the context of a formal clinical review.

2.1.30 Dr C also reported that Mr C's mental health remained stable during this period. Although he had minor physical ailments these were all recorded with intervention within the nursing notes.

2.1.31 The nursing notes confirm the information provided in the summary of 29 September 1999. They also record almost daily urinary incontinence and a weight loss of 4 kilograms in four weeks. Mr C was referred to the dietician who proposed high calorie puddings and potatoes. There is no further record of weight loss and by June 2000 Mr C had returned to his normal weight.

2.1.32 On 13 March 2000 Ms O, Mr C's care manager, telephoned the ward to say that funding had been allocated for Mr C's placement at Hilltop nursing home. However, since he was sixth on the waiting list and his family only wished him to go to this nursing home the funding would be allocated to someone else. Dr C was informed of this decision. He agreed that Mr C should stay in South Ward until a bed was available in the chosen nursing home. At this point Mr V, Mr C's named nurse also tried unsuccessfully to secure a place for Mr C at Beech Day Centre to help him

remain mentally sharp. There is no record of discussion with Mr C Junior about a possible alternative home for his father.

2.1.33 On 3 July 2000 there was a further contact from Ms O to say that funding for Mr C's placement might soon be released. She carried out a further community care assessment. This assessment (which appears to be incorrectly dated 1 June 2000) records Mr C as needing full assistance with all personal care including toileting. He could feed himself and was independently mobile although would wander away if the door was not locked. She reported that Mr C liked going out for walks and listening to music and he enjoyed bus runs in the summer. It was noted that in March 1999 "all parties felt Tom could not return home due to his mental health problems". Ms O concluded that Mr C was to remain on the waiting list for Hilltop. There is no record of any other person contributing to this community care assessment.

2.1.34 On 21 June 2000 the nursing notes record an enquiry from Mr P, Speciality Manager, who was at that time responsible for overseeing the blocked beds in Prince. He wanted to know if Mr C's relatives would consider another nursing home, such as Tulip House, as there was such a long waiting list for Hilltop and funding was now available for Mr C. A decision on this matter was required in three days. Nurse Z telephoned Mr C Junior but was only able to speak to Mr C's wife who felt that Mr C would not want his father to go anywhere except Hilltop. However, she would discuss this matter with Mr C Junior and "get him to look at what is available". On 23 July 2000 Mr C Junior telephoned the Ward to say he would visit to discuss his father's future. There is no record in the nursing notes that this meeting took place. There is also no record in the social work notes that Ms O was involved in any discussion with Mr P or with Mr C Junior about Mr C's placement. Mr C Junior confirmed there had been no such discussion with him but if there had been he would probably have continued to insist that his father went to Hilltop. He also told us that he had had letters from the hospital saying that his father's bed was needed. However, he had not fully understood this since when he visited the ward he often observed empty beds.

2.1.35 The nursing summary notes for this period simply record fortnightly or three weekly ward meetings with Dr C and "no change in current management".

2.1.36 Mr C's uneventful life in South and East Wards continued until he was transferred back to Short Ward in May 2001. During the twenty months Mr C lived in South and East Wards there are three recorded visits from his son. There may have been more as Mr C Junior indicated to us. There were mounting concerns about his lack of clothing and funds which nurses tried to resolve. Mr C was described to us by the charge nurse as a "dead man walking because all his clothes had come from people who had passed away". Mr C Junior told us that he had been upset to see his father not wearing his own clothes and that when he made enquiries he was told they had probably been lost in the laundry. There is no record of any activities or outings for Mr C during this period. There is a record of one visit and two telephone calls from Mr C's Care Manager, Ms O. There was a medical review note on 29 September 1999 and a note in the nursing record of a review by Dr C on 18 August 2000 which stated "ward meeting – reviewed by Dr C. No change in present management".

Transfer back to Short Ward May 2001 and Discharge to Hilltop Nursing Home on 12 September 2001

2.1.37 In May 2001 a clinical decision was made that a vulnerable patient in Short Ward who was at risk of harm from some disturbed patients needed to be nursed in a predominately female environment. She was therefore moved to South Ward with Mr C taking her bed in Short Ward.

2.1.38 We were told that the overall environment of Short Ward had deteriorated since Mr C's last stay there because regular occupational therapy and physiotherapy services had been withdrawn. There were therefore no regular activities for patients. In Short Ward Mr C continued to spend most of the day wandering the corridor and trying doors.

2.1.39 The medical notes for this period simply record Mr C as "a bed blocker awaiting EMI bed with no management problems". The nursing notes refer almost daily to Mr C's urinary incontinence and to a few restless and disgruntled spells. There is no note of any visit from his son.

2.1.40 On 7 September 2001 Ms O notified the ward that Mr C had been allocated a bed at Hilltop Nursing Home. His discharge date was set for 12 September 2001 and Mr C Junior was informed. A care plan was agreed on 11 September 2001 between Ms O, Ms McM, the manager of the home and Mr C Junior. It records Mr C's personal needs including the desirability of his joining activities and outings.

2.1.41 Mr C left Prince Hospital on 12 September 2001 and was reported to settle quickly into Hilltop Home. At a review on 25 October 2001 attended by Mr C, his son, Ms O and a Hilltop staff nurse, it was agreed that the placement met Mr C's needs. He had initially been unsettled; he was pleasantly confused; Mr C and his family were reported to be content with the care provided. At the time of writing Mr C remains settled and happy at Hilltop. He enjoys regular bus trips and concerts in the home. He has had no illnesses. His vision is checked regularly. Staff say Mr C Junior visits his father every four weeks or so and will bring in things he needs.

2.1.42 When we met Mr C Junior in July 2002 he told us he had become disillusioned with the care provided for his father by Hilltop of which he had originally had high expectations. He thought there were insufficient activities and stimulation for his father. He wished his father could spend more time outside. He was upset to see his reduced mobility and use of a zimmer which he thought was the consequence of insufficient exercise. Mr C Junior described how he had visited his father one evening at about 8.00 pm to find residents in their nightclothes just sitting in chairs. Mr C Junior said he had not visited his father's bedroom and did not know who his named nurse was. He had not taken part in the relatives' group. He had not raised his concerns with staff, in part because he did not want to appear a troublesome relative but also because he did not know what standards of care it was appropriate to expect. He also said that he appreciated that more might happen for residents during the day but he could not visit his father then because of his working hours. Overall Mr C Junior was sorry his father had moved from Prince Hospital which he thought provided a cleaner and more cheerful environment, although he realised there was little for his father to do except pace the corridors. He thought that hospital staff had

been more attentive to his father than were the Hilltop staff. Mr C Junior could not recall the names of staff in either place.

2.1.43 Following the meeting with Mr C Junior we immediately visited Hilltop Home unannounced. We were not able to see Mr C because he was out on a bus trip. Discussion with staff and inspection of Mr C's notes and records confirmed that he regularly took part in activities although some were inappropriate for him because of his visual impairment. Mr C had not lost weight, as his son had feared and was reported to be in good health. Mr C did not regularly use a zimmer.

2.1.44 We have reported Mr C Junior's concerns to the Scottish Commission for the Regulation of Care and we have encouraged him to raise these with the staff of Hilltop. Mr C Junior now has a copy of the National Care Standards for Homes for Older People to help him judge what expectations are appropriate. We have suggested that specialist services for visually impaired people might be able to provide activities appropriate for Mr C's needs.

2.1.45 There have been consistently positive reports on Hilltop from those interviewed by the Inquiry Team who know the home. We have visited Mr C there on three occasions and asked those responsible for Mr C about his life at Hilltop. We have been pleased to see substantial improvements in Mr C's quality of life following his discharge from Prince Hospital. The Commission's primary focus is on the needs of individual patients. Therefore, before we analyse particular aspects of Mr C's care while he was in hospital, and the circumstances which contributed to his lengthy stay there, we describe a typical day in Mr C's life while he was a patient in Prince Hospital and a typical day now he is a resident at Hilltop Nursing Home. The following information was obtained from interviews with medical, nursing, social work and nursing home staff, access to medical and nursing notes and visits to the old age wards in Prince hospital and Hilltop nursing home and from Yshire Health Board's Annual Inspection Report of Hilltop Home in August 2001.

A Typical Day in the Life of Mr C while in Prince Hospital

2.1.46 During the three years that Mr C spent in Prince Hospital he woke early, sometimes at 4 a.m. or 5 a.m., as he was accustomed, having been a baker. However, he usually got up between 7-9 a.m. Nursing staff helped him to get dressed, as he needed assistance, and he then had his breakfast in the dining room. After breakfast, he was given his medication. According to one of the named nurses, Mr C was often reluctant to take his medication, so it could take up to half an hour to persuade him.

2.1.47 His routine in the admission ward, where he spent seven months, was to walk about the corridor until the Occupational Therapy Reality Orientation group, which ran Monday - Friday mornings from 10-11. Thereafter he had a cup of tea and twice a week, he attended the Physiotherapy group, where he participated in exercises, playing skittles and other games.

2.1.48 In the continuing care wards, and on return to Short ward, there were no activities. One senior charge nurse stated that, "Activities were subsequently just what the nurses could provide." Another senior charge nurse commented that, "In the continuing care wards there is hairdressing, chiropody etc., but no occupational

therapy activities. The nurses' job is to keep the patients comfortable and ensure that their diets are adequate. There had been an activities nurse, but due to staff shortages and sickness, this is not done anymore."

2.1.49 Mr C's morning was spent walking up and down the linoleum corridors, occasionally trying the locked door. One of the consultants described Mr C as, "difficult to engage in any meaningful conversation, contented most of the time, overactive at times, going up and down the corridor a lot". A named nurse said "It was really the nursing staff who had tried to keep him occupied, as there was not a lot of input from occupational therapy or anything in the ward, but a lot of time he just spent wandering."

2.1.50 Mr C would talk to the domestic staff and the nursing staff, when they had the opportunity, as most of the other patients required more intensive nursing care. One of the named nurses commented, "Mr C was quite cheerful and quite contented and he enjoyed interaction with the nurses. Options for socialisation had been limited. He had a warm smile and was very friendly. He used to wander about or he just sat and talked to staff, in between their jobs and as they were doing things. He was a great favourite."

2.1.51 Staff stated they would have liked to have the time to sit down with the patients, but due to staffing levels, they could only provide the basic nursing care to their patients.

2.1.52 In the continuing care wards, Mr C was the only mobile patient. One of the senior charge nurses stated that, "Mr C had been the only mobile patient they had at the time and had been free to wander. That had been how he filled his day. Because Mr C had been one of the few patients you got feedback from, he probably had more time spent with him than the other patients."

2.1.53 On his return to the acute admission ward, most of the patients were in the acute phase of their illness, therefore their behaviour was more disturbed and the environment was noisy and disruptive e.g. people constantly asking to go home. According to the nursing staff, Mr C frequently said, "That man's awfully loud today."

2.1.54 After lunch, in all of the wards, Mr C slept for a couple of hours until teatime at 3 p.m. Mr C then spent his time wandering up and down the corridors again until suppertime. Staff tried to get time to sit down with him and talk or read the paper to him, if staffing permitted. Unfortunately he could not play dominoes or cards because of his visual impairment. However, he still enjoyed music and he used to sing quite a bit. He also listened to the television and radio. He had the opportunity to go out into the ward garden and sit on the benches when the weather permitted. However, his main occupation was wandering up and down the corridor and talking to staff. A Senior Charge Nurse said "Staff blethered to him about football and things. He sometimes asked how Celtic were doing and he sat and chatted when the nurses were feeding someone else at teatime. He had been a character." One named nurse recalled that, "Tom was in his element speaking to people and domestic staff in the ward." Another senior charge nurse described Mr C as, "very witty and could recall events from way back."

2.1.55 After supper, Mr C had a bath and retired to bed. The routine would begin again the next day.

2.1.56 Mr C spent some of his stay in hospital in a 6-bedded dormitory and also for a brief period in a single room, where he had en-suite toilet facilities. He had no personal possessions and few visits from his son. The number of patients he lived with varied from 14 –18. The ward environment was bare, bleak and lacking stimulation. Hospital staff and representatives from the Mental Welfare Commission's hospital visiting programme acknowledged this.

2.1.57 Mr C was clearly well liked by nursing staff who spoke fondly of him, as evidenced by their comments. The staff wanted to take him out and provide activities for all their patients but staffing levels prevented this. They wanted to make the ward environment more homely, but the layout and decoration did not lend itself easily to change.

A Typical Day in Mr C's Life at Hilltop Nursing Home

2.1.58 Hilltop is a private nursing home. There are 59 beds, split into two units. Mr C was admitted to the dementia unit, which caters for 28 people. He shares a two bedded good-sized room with another gentleman, who had been admitted from Prince on the same day. He still has no personal possessions in his room. The bathroom facilities are outside his room.

2.1.59 The environment is very homely and welcoming. There are fitted carpets, sofas and pictures in the hall and a huge fish tank in the main corridor. Although the sitting/ dining room is small for the total number of residents, there is also a small 'reminiscence' sitting room. Residents have access to their rooms anytime and the way the sofas have been placed gives extra sitting areas. The observations of the Commission staff are similar to the comments made in the positive report of Hilltop Nursing Home in the report of Yshire Health Board Registration and Inspection Unit after an inspection in August 2001.

2.1.60 Mr C gets up when he wants, although it is still early. Staff prompt him to wash and dress. Once he has his breakfast and medication, he goes to the sitting room and chats to the other residents and staff or has a walk along the corridor, until the two Activity Co-ordinators arrive at 10am. Mr C likes talking about football. Depending on the activity programme which includes art, exercises, music, dancing, Mr C can participate or not, depending on his wishes. Mr C loves to dance. He always enjoys his tea mid morning. After lunch, he has a sleep. Activities are also available in the afternoons and every day Mr C has time with his named nurse. Tea and coffee are available any time. Mr C loves chocolate, especially chocolate biscuits and Maltesers. His individual nursing care plan is reviewed every two to four weeks. Residents' participation in activities is regularly recorded.

2.1.61 There is a light evening meal and supper later on if residents wish that. Mr C still spends quite a lot of time walking up and down the corridors. There is a higher ratio of staff than in the hospital for Mr C to chat to. According to his named nurse, he 'loves the crack'.

2.1.62 There are always visitors in the nursing home. School children also visit and student placements from the local colleges are encouraged. Mr C receives some visits from his family. The nursing home has its own mini bus and driver and residents go on outings once a week. Mr C has the opportunity to mix with others with whom he can talk in a more stimulating, homely environment. Concerts are also organised on a regular basis.

2.1.63 As in the hospital, the nursing staff provide a good level of care. Dr A had seen Mr C in Hilltop and stated that, "he is very settled and contented." One of his Prince named nurses commented that, "Mr C had been in Hilltop when he (named nurse) followed a patient who was in transitional care. The staff there had been very warm and positive and it had been good."

2.1.64 Mr C's care manager described Hilltop as, "a well sought after home, a very homely nursing home. It has a wide range of social activities. There are bus runs in the summer and a more normal setting than the hustle and bustle of the acute hospital environment. They have musical events every week, which Mr C enjoys and a more relaxed environment. It is a better quality of life for him."

2.1.65 Mr C told the Mental Welfare Commission's staff who visited him that he likes the new place. Although it was clear that Mr C could recollect little of his stay in Prince Hospital he said he liked that place too.

2.2 The Management of Mr C's Funds and Property

Mr C's Assets

2.2.1 We were told that while Mr C lived in his own home, a rented council house, he managed his own funds. A social work services financial assessment in July 1998 records his income as being £70.46 retirement pension, £36.59 income support and £34.30 attendance allowance. He received full Housing Benefit but paid £8 per month Council Tax. This financial assessment also showed that Mr C had two Halifax Building Society accounts amounting to £5,367. The respective balances six and twelve months earlier had been £6178 and £6446. In November 1998 Mr C's capital was reported to be £4884.

Funds for Mr C while he was in hospital

2.2.2 After Mr C had been in hospital for four weeks his attendance allowance would have stopped. After six weeks his state retirement pension would have been reduced by approximately £27. After a year he would only have received his personal allowance of approximately £14.

2.2.3 Less than three weeks after Mr C's admission to Prince Hospital he signed, on 5 January 1999, a Power of Attorney in favour of his son (see para 2.1.13). Mr C Junior would then have been able to deal with all his father's funds.

2.2.4 Before Mr C was declared Incapax in July 2000 the only record of funds held on his behalf is contained in his patient's profile in East Ward dated 5 July 1999. This notes that 'Visitors appear to visit ward infrequently. Relatives have had to be contacted for funds, clothing, money for toiletries etc.' This profile also notes that Mr C Junior has Power of Attorney and has provided some clothing and money and is willing to co-operate. However, from 3 May 1999 to 1 October 1999 the records show Mr C had no funds available to him. From October 1999 Mr C Junior agreed to provide money for his father and modest balances (£7-£16) are recorded until May 2001 when the hospital managers became appointees for Mr C's retirement pension following approaches to his son by nursing and social work staff.

2.2.5 Although nursing staff were able to secure some funds from Mr C Junior for his father's everyday needs from July 1999 they expressed considerable concerns about his need for clothing. They estimated that about £360 needed to be spent (see paras 2.1.24 and 2.1.25). Both Mr V, Mr C's named nurse, and Ms H, Senior Charge Nurse had tried to sort out these problems directly with Mr C Junior. In September 2000 they discussed with him the benefits of a hospital account for his father. Mr C Junior was reported not to be hostile to these requests; he was simply unresponsive. Mr V told us that he contacted the charge nurse and Mr C's care manager about these problems. Ms H told us that when Mr C Junior continued to fail to provide clothing, despite being given his father's measurements, she wrote to the clinical nurse manager in November 2000 asking for the matter to be taken further. Mr C Junior told us that he was very surprised to receive a letter from the hospital saying his father needed £300 worth of clothing. He could not see how much expenditure could be necessary. He and his brother had from time to time taken clothes in for him.

2.2.6 Ms O told us that when she had been informed by Prince Hospital in February or March 2001 that Mr C was not receiving his personal allowance and also needed clothing she discussed these matters with Mr C Junior. She informed us that Mr C Junior had been extremely apologetic about these financial problems saying that he knew he should have been more attentive to his father. Ms O also told us that she thought Mr C Junior found it very difficult to visit his father because he was upset by his dementia and the ward environment.

2.2.7 As well as discussing these matters with Mr C Junior Ms O contacted the Benefits Agency in March 2001 to ask whether an appointeeship could be made in favour of the hospital. She was told that because Mr C Junior had Power of Attorney, a fact at that time unknown to Ms O, it would be difficult for the hospital to hold the appointeeship. However, because it had been reported to the Benefits Agency that Mr C was not receiving his personal allowance a visit would be made to his son. Ms O then learned that during this visit Mr C Junior said that he was quite happy to give his father's pension book to the hospital and for the hospital to be the appointee. The pension book was handed into the hospital on 30 March 2001 and, after Mr C Junior had given his written consent, the hospital became Mr C's appointee and received his £14.85 personal allowance each week. No other bank or building society books were lodged with the Patients' Affairs Office. Mr C Junior told us he was very happy with the present arrangement for his father's financial affairs. He thinks there is £200-£300 in his account. He responds to any requests from Hilltop Home. Staff there spoke positively about Mr C Junior's prompt responses.

2.2.8 Ms S, Patients' Affairs Officer, told us that she had not been contacted by anyone regarding Mr C's financial problems. Had this been done she said she could have made enquiries and perhaps have taken steps to resolve some of the problems. When Mr C was made Incapax in July by Dr C for eight to nine months, before the hospital had Mr C's pension book, there was very little in his account. Deposits of £20-£25 were made each month from September to December 2000 but nothing after that until May 2001 when the hospital received Mr C's pension book and £58 monthly was paid into his account thereafter.

2.2.9 After his discharge to Hilltop Nursing Home Mr C had £379 in his hospital account. Ms S told us that she had informed Social Work Services and Mr C Junior about these monies but there had been no request for them to be transferred.

Mr C's Capital

2.2.10 We have already noted that in July 1998 Mr C had £5367 in his two building society accounts. When reviewing the Social Work Services case notes the Commission noticed that a financial assessment carried out in July 2000 records Mr C as having only £76.42 remaining in these two accounts. A further financial assessment carried out in July 2001 records these same assets. It is also noted in these forms that in 1998 there had been £4824 in Mr C's account and that there is evidence of a large withdrawal of a lump sum. It appears therefore that Mr C's capital which in July 1998 had been recorded as £5367 had, by July 2000, virtually disappeared. From October 1998 Mr C was in respite care until he was admitted to Prince Hospital in December 1998, leaving there in September 2001. Mr C Junior told us that he had used these funds to pay his father's outstanding utility bills, a large bill for backdated

Council Tax and the rent for his father's flat which had been kept on for about five months. Mr C Junior also told us that his father had said that if he needed some financial help he would be happy for some of his capital to be used. Mr C Junior urgently needed a car and had used £1,200 of his father's capital to buy one at a car auction.

2.2.11 The social work notes record that in July 2000 Mr C Junior contacted Ms O to say that his father had no funds to pay outstanding Council invoices for about £1,200 for respite and home care. Ms O recommended to the Council that these bills should be discharged and this was done. Ms O also said that it was not unusual for the Council to discharge bills for someone who had dementia.

2.2.12 In October 2001 the Commission sent Ms O a list of questions we wished to ask her during the Inquiry, including questions about Mr C's finances. When we met Ms O in December 2001 she told us that she had been dismayed when she realised Mr C's capital had been depleted and that these funds may not have been spent on him. She also realised that for over two years Mr C Junior had been receiving his father's personal allowance and that during this time it was apparent that only small sums had been paid to the hospital for his father's needs.

2.2.13 Ms O told us that when she had noticed the depletion of Mr C's capital she had contacted the Council's legal adviser Ms McP by memos on 25 July and 28 August 2001. Ms O told us that in the first memo she had suggested that in order to protect her relationship with Mr C Junior Legal Services should write to him about the depletion of his father's funds. Ms O also said that her team leader had spoken as well to Ms McP. They had felt that because Mr C Junior had Power of Attorney there was little that could be done. The matter had therefore not been raised with Mr C Junior. It had also been decided not to refer the matter to the Public Guardian because the Power of Attorney had been granted before the implementation of the Adults with Incapacity Act 2000. It was thought therefore (incorrectly) that the Public Guardian could do little. In a written note Ms McP told us she had advised Ms O to ask Mr C Junior what the withdrawals from his father's account were and, if there was not a satisfactory response, to make a referral to the Public Guardian. She gave this advice because Mr C's funds, even before depletion, had not been at a level which would have required him to contribute to his care home costs. Enquiries would not have to be made for that purpose. However, because of the Public Guardian's new remit in respect of Powers of Attorney under the Adults with Incapacity Act she thought referral to him would be appropriate if there was no satisfactory response from Mr C Junior.

2.2.14 Further Social Work Services notes were sent to the Commission on 27 November 2001. They are entitled **Late Additions to Case Notes** and are dated 26.11.2001. These notes record that in July 2001 the financial reassessment was completed by Mr C Junior and in August 2001 it was noted that there had been a depletion of funds from Mr C's bank account. The notes further state that Ms O had been advised by her team leader to contact Legal Services on 28 August 2001. This was done via a memo of the same date which stated that Mr C was awaiting funding at Hilltop and that Ms O had noticed on financial reassessment that his son had 'emptied his bank account from £3365.12 to £70.28 (the capital sum at the actual financial assessment is £4824.) The note further states that the hospital is now appointee for Mr C's pension

book ‘as the son did not pay over the personal allowance on a regular basis’. Ms O concludes by saying that she doubts if there is anything that can be done legally because of the Power of Attorney being in force but, ‘in the light of the new laws of incapacity I wonder if anything can be done’.

2.2.15 An earlier memo from Ms O to Ms McP dated 25 July 2001 is confusing in that it states ‘I discussed your response in respect of writing to Mr C junior with Mary Jones my team leader. We both feel that in order to protect my working relationship with the family that Legal Services write on my behalf’. It appears from the case notes that the discussion referred to in this memo took place on 28 August 2001. It seems that the two memos have been incorrectly dated since the content of the memo dated 28 August 2001 appears to pre-date that of the memo dated 25 July 2001.

2.2.16 The social work notes go on to record that on 11 September 2001 an e-mail from Ms McP to Ms Jones responding to the second incorrectly dated memo, advised that it would not be appropriate for her (Ms McP) to write to Mr C as ‘it is not a legal issue but a welfare issue in terms of possible financial exploitation of Mr C by his son. There also is no issue that the level of funds were such that Mr C would have been self-funding’. Ms McP wrote to us noting the matter did not require a response from the Council’s legal adviser; it was an issue which related to social work practice.

2.2.17 Ms McP again suggested that Social Work Services could contact the Public Guardian. However, on 12 September 2001 Ms Jones and Ms O agreed that, as the Power of Attorney for Mr C had been set up prior to the Adults with Incapacity Act and as they thought (incorrectly) the Public Guardian could only act if the Power of Attorney is registered since the new legislation, nothing could be achieved by challenging the son and no further action would be taken. They did not seek further legal advice from Ms McP.

2.3 Responsibilities for Placing Mr C in a Nursing Home

2.3.1 All those we interviewed told us there were very long waits for nursing home placements in Ytown for people with dementia. There were only two homes with elderly mentally infirm units; a third home had been closed in 1997 and the beds had not been replaced. Hilltop was the most popular nursing home and there could be as many as twenty-two people on its waiting list. In 1999 relatives were not asked to select more than one home and there was no policy or practice of asking them to reconsider or widen their choices to hasten the discharge of patients from hospitals.

2.3.2 From the beginning of 1999 to March 2001 after a care manager had made an assessment that a nursing home placement would be appropriate, and this recommendation was endorsed by a line manager, the decision about funding rested with a single service manager who was responsible for allocating funds throughout Yshire. This was Mr Smith, now no longer a Council employee. We were also told that Mr N's manager (Mr Peter then a senior social work manager and also no longer an employee of Yshire Council) had decided in 1999 that, for at least a year, there would be no admissions from hospitals to community placements.

2.3.3 We were told that this 'policy', which does not appear to have been discussed or agreed elsewhere in the Council, had lasted for thirteen months. We were informed that there had been no written memorandum about this policy; it had simply been passed down the management line. It was suggested to us that Mr Peter had taken this stance because it was believed the Health Board had not made adequate resource transfers to the Council. We were told that this situation was very stressful for care managers who were responsible for people in hospital. They were put in a very awkward position with relatives and hospital staff. They knew that even if a vacancy occurred there would be no funds for it. Because patients' and carers' choice of placement was to be respected funding and placement had to match, a system which continued until Mr C was discharged from hospital. This meant that if funds became available for Mr C's placement, as they did twice before he was eventually discharged in September 2001, but there was no bed in Hilltop, the funds would pass to another patient. If a vacancy became available but there were no funds this place would be given to someone else. In a letter to the Commission dated 7 March 2001 Mr N, Service Manager, confirmed that when funding had been available for Mr C's placement there was no vacancy and that when vacancies occurred there were no funds. We were told of no system to try and align funds and vacancies or, until March 2001, of any attempt to draw up a systematic waiting list. The matching of funds and placements was simply a matter of chance.

2.3.4 Equally we were told there were no predictable funds for community care placements. Although the Council would allocate a budget each year for these placements blocks of money might then become available from the Health Board to deal with particular bed blocking crises or with winter pressures. 'Sometimes these recurred and sometimes they did not.' These winter pressure funds from the Scottish Office and then the Executive were described by one respondent as a 'kind of bizarre Christmas present' in that once they were used to place more people in nursing homes, because the funds did not recur, the debt for the Council simply became larger, making it more difficult to place other patients. In such an environment it is not surprising that many respondents we interviewed – consultants, social work managers and care managers -

told us of their resignation about delayed discharges and their impotence to effect change.

2.3.5 In March 2001 Mr N became responsible for care management services for all groups except people with learning disability and those under sixty-five with a mental health problem. He also held the budget for the purchase of residential and nursing home care.

2.3.6 Mr N told us that Mr L, the new Senior Operations Manager, wanted to move from decisions made by a single manager to a more collective system. Therefore in June 2001 a Joint Funding Panel had been formed which met every week. The members included the bed utilisation manager, the clinical nurse manager and the delayed discharge co-ordinator. The Panel would know each week what funds were available for placements; there might be only three or as many as eight to ten. Each application for funding, including emergency admissions to care homes and all delayed discharges, were scrutinised each week. The Funding Panel had been told that, because of the delayed discharges, approximately a third of the funds available to it must be allocated to these patients' placements. We were subsequently told that this money was usually substantially or completely used up by a rota system whereby each week and in turn the two large hospitals and the community hospitals would be allocated funds for the placement of one of their delayed discharge patients. Apart from these placements there were rarely sufficient funds to enable regular discharges from hospital because of commitments to people already in the community.

2.3.7 Information was made available to the panel about the number of patients whose discharge was delayed, when they had been assessed and the length of time they had waited. It had quickly become apparent that Mr C was at the top of the waiting list. However, time on waiting list could not be the only determining criterion. Risk also had to be considered. There were also cases which 'trumped' the system; these were people who had been admitted to care homes in an emergency and who could now not return home. Their placements were a "fait accompli" which the panel had to acknowledge.

2.3.8 Another change which came about with the formation of the panel is that families are now asked to select second and third alternative placements although we were told that, only very reluctantly, if at all, would people be placed in a home which was not the first choice.

2.3.9 When Mr N spoke to us in December 2001 he estimated there were around seventy-five delayed discharge patients in Yshire; of these over twenty were people with mental health problems. In January 2002 the Inquiry Team was given sight of the bed monitoring report prepared for the panel in early December 2001. This showed that there were now over thirty patients awaiting discharge in Prince Hospital. This included a number of long-stay patients who had recently been identified for discharge through resource transfer monies. The report also included information about patients under 65. This showed that seven patients had been waiting between 140 and 540 days. The remaining patients had waited between 73 and 8 days. Those waiting the longest needed placements in specialist settings.

2.3.10 Mr N told us that the hope was that the budget for domiciliary care and care home placements would become larger but that it also would consist of more regular and predictable payments. Placements should not depend on 'lucky money and the availability of care'. The new system would also make it clear if someone's discharge was delayed because some minor (say £200) expenditure was needed from a depleted budget, for example, for occupational therapy adaptations. In such cases money would be made available by the panel.

2.3.11 The Inquiry Team noted that the ISD data showed that between July 2001 and January 2002 there had been some modest reductions in the number of Yshire patients in mental health specialties who had been waiting for funding for their placements for more than six weeks. The figures for April 2002 show more substantial reductions. Unfortunately this improvement was not sustained and by July 2002 the number of patients waiting for funding had increased.

2.3.12 It appears from Social Work Services records that care managers could also help the panel with information. We noted a memo dated 15 June 2001 to Mr N from Ms O which stated that Mr C was third on the list for Hilltop. This was followed by a letter from Ms O to Ms McM, Manager of Hilltop, dated 27 June 2001, which stated that Mr C was now top of the list of the five people waiting for Hilltop.

2.3.13 Ms O told us that she remained the case-holder for Mr C and other delayed discharge patients in Prince Hospital 'until the funding and the placement came together'. However, her contact with patients would not be frequent because there was no active work to be done. It was not her role to champion Mr C's cause. She, like other care managers, knew and accepted there would be lengthy waits for community placements.

2.3.14 Ms O also told us that the system established by the Funding Panel had greatly improved matters. There was now regular information for care managers about placements funded and about waiting lists and the Panel was gradually working through the delayed discharge patients. This was encouraging. However, we were also given some information from other respondents which appeared to cast some doubt about the future working of the Funding Panel. Mr N told us that there would shortly be a change of membership with the advent of Yshire Joint Future and that this could change the Panel's priorities and systems. Mr P told us that the Panel was still working on its criteria, and Ms M said there was a debate about whether the responsibilities of the Panel would be disaggregated to each locality. In September 2002 we were informed by senior management that these possibilities had not come to pass. The Panel continues to operate as it had done previously. Only the chairmanship of the Panel had changed.

2.4 Of Managers and Money

2.4.1 According to ISD data Yshire had had high numbers of patients whose discharges were delayed because of lack of funding since this data was first collected in September 2000. It is clear from managers interviewed and from papers submitted to the panel that this matter was of long-standing concern to Yshire Board, Yshire Primary Care Trust and Social Work Services. However, we were also told that several major changes in the social work services senior management team had made it difficult to establish consistent priority systems for community care. In 2000, a result of Yshire Council's restructuring, a department of social work and housing was established. The Director of Social Work and Housing retained overall responsibility for social work, including community care and acted as Chief Social Work Officer, There were three Heads of Service – for social work, housing and strategic planning. There were then further changes. Mr L was given overall responsibility for social work, including the Joint Future agenda, while the then Head of Social Work led the day to day social work operations. In 2001 Mr M was appointed as interim Head of Service (Social Work) and then assumed some additional responsibilities in 2002.

2.4.2 When we met Mr M in February 2002 it was not clear to us what arrangements there would be for a lead social work officer within the Council. We were told that Mr L would be the contact for the Commission in respect of community care matters but an integrated service manager would be responsible for all operational services for health and community care. This person would have direct responsibility for delayed discharges while Mr L remained the accountable officer. We were later informed that Mr L had moved to another post. At that point Mr M became Interim Chief Social Work Officer.

2.4.3 The major reorganisation of community health and social work services followed research in the Yshire area which showed, unsurprisingly, that people wanted services provided efficiently, quickly, with as little intrusion in their lives as possible and without being passed from one department and agency to another, with little support available for carers. It was agreed that a fully integrated and flexible health and social care service would be established for the whole of the adult population in Yshire. There would be integration at the planning, commissioning and financial level as well as in-service delivery.

2.4.4 This plan, which would bring about major changes in the organisation and delivery of health and social care services was expected to deal directly with some of the problems which contributed to delayed discharges. At the same time the Board, Trust and Social Work Services were involved in a number of activities which were intended to address, in the shorter term, delayed discharges for all patient groups across the region.

2.4.5 A joint workshop in February 2000 agreed a number of proposals to reduce delayed discharges. These included improvement in home care services, stricter gate keeping for residential and nursing home care and improved discharge procedures. It had also been agreed in January 2000 to 'establish a slimmer more inclusive model for strategic planning and implementation – the joint Health and Community Care Executive Group'. Five task groups would also be established, including one for

older people and one for people with mental health problems. They would develop strategic plans and be represented on the Executive Group.

2.4.6 The Planning and Development Group then established a delayed discharge group whose task it was to develop proposals for implementing the proposals made in February 2000. The Inquiry Team was given papers describing various seminars and meetings which were held in 2001 to consider delayed discharges. The purpose of these meetings was to raise awareness of these issues and to consider feasible ways of addressing problems.

2.4.7 In January 2001 it was reported to the Group that the total number of delayed discharge patients in the Yshire Primary Care Trust NHS was nearly 300, the equivalent of an average district hospital and representing almost 13 per cent of all occupied beds. Sixty eight per cent of these patients exceeded the nationally accepted planning period for delay of six weeks. Twenty eight per cent of the Yshire Primary Care Trust delayed discharge patients were in Yshire Council.

2.4.8 At an unknown date, but probably early in 2001, a local outcome agreement was agreed between Yshire Health Board, Yshire Primary Care and NHS Trust, Yshire Local Health Care Co-operative, (LHCC) and Yshire Council. The purpose was to reduce delayed discharges in Yshire, with a target of 20 per cent reduction by March 2002. This agreement includes a detailed action plan dealing with the expansion of home care options, an extension of the range of options for discharge, the transfer of patients in acute wards direct to the community; the estimated cost was over £2¼ million. This action plan also includes some cautionary comments about the restrictions on the LHCC and Social Work Services budget. Nevertheless, the overall target of a 20 per cent reduction in delayed discharges was retained. With reference to the financial framework it was stated that 'resources will be aligned with the Yshire Joint Future approach to underpin the whole systems methodology, with clearly stated financial commitments from each of the partners. We will co-operate in such a way as to recognise the financial restraints and accountabilities which operate and will collaborate to manage the financial and other pressures within the system'. The £2¼ million pounds was then allocated to different bodies within Yshire.

2.4.9 In August 2001, at the request of Mr L, Senior Operations Manager, a meeting between all the responsible bodies was held to address the continuing problem of delayed discharges. It was agreed that significant resources would need to be in place to deal with winter pressures. A small executive delayed discharge group was established 'to pull together current working and action short-term plans'. This group would closely monitor delayed discharges and the outcomes specified in the local outcome agreement. It was acknowledged that significant steps had been made by all agencies in reducing delayed discharges but that some 'fast tracking of consolidating this work before the winter season was essential'. A detailed six page action plan was produced with lead officers and timescales for a range of activities which include agreed resourcing for the funding panel, improvements in health and social care integrated teams, augmenting care packaging, reviewing resources available to professions allied to medicine and reviewing admission criteria for emergency respite.

2.4.10 The objectives of this action plan and the implications for service delivery were not referred to in specific terms by the managers we interviewed. However, we noted that

the 20 per cent target for delayed discharges remained in a paper, now entitled a Draft Action Plan, which was attached to a background paper for a Joint Management Forum dated 13 December 2001, some five months after the meeting referred to in the previous paragraph. This Draft Action Plan (which refers to the whole of the Yshire area) also aimed to establish a long-term strategy by 31 March 2003; a Yshire Action Team which would review and co-ordinate the overall Action Plan; and a joint information system. The strategy would also include, without a target date, a funding proposal for nearly 140 additional care home places. The commentary attached to this plan notes that the creation of additional nursing home places is not national policy and refers to the Joint Future agenda. It acknowledges that, with an average length of nursing home stay of 18 months, considerable resources will be tied up in this provision. However, with more than 150 people in Yshire assessed as requiring nursing home care no practical alternative was envisaged for this group. The Action Plan also refers to the importance of provision which, by preventing hospital admissions, will in future affect the numbers of delayed discharge patients.

2.5 Funding for Placements in the Community

2.5.1 The Yshire Joint Community Care Plan 1997-2000 states that, in addition to DSS transfer monies, the Social Work Department would be making use of about £260,000 made available during 1997-98 by Yshire NHS Trust and Yshire Health in resource transfer funding as a result of the closure of a ward in Ytown General Hospital. The plan goes on to state that agreement has been reached between Yshire Health and Yshire Council which indicates, *inter alia*, that during 1997-98 nearly £650,000 will be made available to provide alternative placements for patients who have previously been, or are in the process of being, discharged from long-stay hospital care.

2.5.2 The plan refers as well to the differences resulting from the PES settlement for 1997-98 which shows that 'health receives an uplift of 1.5 per cent in real terms nationally against a short-fall of 2.3 per cent for local government. Yshire Health is to receive, after adjustments, an initial £6.3m in resources. This will be used to support a variety of developments across the whole of Yshire Health, including those affecting community care in Yshire'.

2.5.3 The 2000-2001 review of this Joint Community Care Plan refers to substantial increases in resource transfer being assumed, particularly for mental health. The review paper also states that Yshire would benefit from additional funds being made available by the Government, to influence Winter Pressures and Delayed Discharges in particular. It further states that the Health Board had transferred to Social Work Services £1.5m for community care services. This was the proportion of the Health Board savings resulting from the reduction in the number of long-stay NHS beds negotiated to fund the additional community care services required. We were later told that in 2000/2001 the budgets to Adult Care Services and for Mental Health and Social Work Services had each been increased by over half a million pounds. In line with national policy the management allocated these monies to community based services not to care home placements. This is a more cheerful account of community care funding than the one given to the team by interviewees. Despite this apparent major increase in funds available, community care managers at all levels, and therefore, not surprisingly, frontline staff as well appeared to believe there was virtually no money for community care placements.

2.5.4 A theme running through nearly all the interviews undertaken by the Inquiry Team was the inadequacy of funds for community care in Yshire. It has, however, proved impossible to obtain detailed information from the Council about the annual budgets for nursing home and residential care during the time Mr C was in hospital, or about the relationship between these budgets and those for other community services. We were given some conflicting information from the Board and the Council about the resource transfers for services for people with mental health problems in Yshire. However, we were later told that the Council and Board meet regularly to agree resource transfer funding and that with the major restructuring these arrangements have been consolidated.

2.5.5 It was quite clear from the interviews with staff that the terminology they used when discussing finance was totally confusing. The terms resource transfer, non-recurring monies, year end windfalls, delayed discharge monies, pump priming funds, joint funding initiatives etc, could be used incorrectly and some interviewees described a

particular source of revenue in differing ways. This all contributed to a very confused picture for the Inquiry Team and for many staff. Even finance staff in each responsible body, who were very open and helpful, tended to define these terms in differing ways. However, we were later told that the Resource Transfer and Bridging Protocol which was agreed by all the Yshire health and local authorities in January 2001, defines key terms (see paras 2.5.14-2.5.15). When we met Trust and Council staff about twelve months after this protocol had been signed the definitions were not being universally used. One consequence of this confusion was that staff came to accept an assumption that there was no money for delayed discharge placements and so nothing to could be done to expedite the discharge of patients like Mr C.

2.5.6 The Finance Director in the Trust, Mr Q, gave details of the resource transfers which had taken place in 2001-2002 in relation to the rationalisation of the services on the Prince site and confirmed that no previous transfers had been made to Yshire Local Authority from this source. He advised that resource savings from the reconfiguration of Prince which had taken place in previous years had been used to support local dementia units and to increase hospital day provision. In previous years he advised that considerable sums had been transferred to Yshire but these were mainly for other client groups and that only a small amount had been transferred in relation to mental illness. It was suggested that this was one of the main reasons why a decision had been taken by Mr Peter that no Council funds would be used for delayed discharges from Prince during 1999/2000.

2.5.7 The Finance Manager in Yshire, Mr R, confirmed Mr Q's assessment of the financial transfers and, although there were differences in the description of the source of the funds, the figures largely bore out the overall position. Although we requested the budget figures from the Local Authority for Care in the Community expenditure this was not forthcoming mainly, it was advised, because of the different management arrangements in Yshire which did not allocate finance on the basis of the same client groups as the Trust and Health Board. Following the major reorganisation the current management structure is locality based across client groups and the budget arrangements had not yet been realigned. Frontline staff were left very confused by these changes.

2.5.8 Mr R raised two important issues with the Inquiry Team about the lack of financial flexibility at the time of Mr C's hospitalisation. These referred to the internal workings of the Council with regard to the budget management of community placements. Mr R's role had been to advise the then Social Work team of the available funds against both actual and committed expenditure and to give general financial advice. In the event his input was not at a level he had anticipated. Budget meetings tended to focus on whether the figures were correct or not and he was then requested to leave the meetings when decisions were then taken without the benefit of a professional finance input. "Finance had been seen more as a bean counter". Although budget information was available to senior managers the Financial Manager was not involved in decision making. At that time he also had no professional or managerial link to a Director of Finance who would have had the necessary seniority to rectify matters. Mr R thought that with a little more flexibility in financial management Mr C's situation could have been resolved much earlier. Mr R indicated that the situation had recently changed and that he was now fully involved

in decision making. He also had a managerial line for reporting problems should this be necessary.

2.5.9 Mr R gave the Inquiry Team some helpful information about the management of the residential and nursing care placement budget. This is held centrally while all other budgets are devolved to localities. We were told that in 1998-99 placements were made under this budget in accordance to the assessed risk to the client and the monies which were available. Placements were authorised by the service manager, Mr Smith, with Mr Peter as budget manager. The present management of this budget is still held centrally although placements are considered by a Funding Panel which includes representatives from the Acute and Primary Care Trusts and from Social Work Services (see paras 2.3.6-2.3.8). The Panel considers risk for clients, alternative care packages and available funding. Mr R had now appointed one of his colleagues to advise this Panel and help with discussion about sources of funds. Mr L told us in January 2001 that the budget arrangements would change in preparation for Yshire Joint Future. The long-term aim was to devolve the budget to each of the Yshire localities which could then be responsible for quick and flexible decisions.

2.5.10 Mr R confirmed the anxiety expressed by Mr N (para 2.3.4) about the problems associated with placements from non-recurring winter pressure monies. Social work services would be able to place ten to twenty people in January who would not otherwise have had these placements but in April the department had to pick up the full costs for these clients. This directly affected who could be placed in the following year. Careful financial planning was needed to take account of these non-recurring monies to avoid a situation that had prevailed until recently in which 'management got the money in January and forgot the big hit in April'.

2.5.11 We were told by Mr R that financial and service planning has now improved in that the Finance Department will now be involved directly in discussions about planning and service delivery with the senior managers in the Trust and the Council. Previously Mr R had simply met with the Council heads of service each month and most of the discussion had been about keeping within budgets. Decisions would not be made at these meetings because so much time was spent analysing the small print of the figures. We were told that it helped greatly for Finance to be involved with service planning and to help with the setting of targets for delayed discharge. Although these were ambitious Mr R thought that the 20 per cent reduction in delayed discharge was being met.

2.5.12 Mr R thought that early in 2002 there was still some lack of clarity about resource transfer but efforts were being made to link accurate information with service planning. Mr R told the Inquiry Team that, in his opinion, until the last two or three years, Social Work Services had been operating within a centralised decision making framework, with little development of budgets. There was little strategic planning or flexibility. This situation had now changed. The advent of locality budgets would provide more flexibility for managers who would also receive training in financial management. Steps were being taken to link financial and service planning for particular groups such as people with dementia, physical disability, learning disability and so on. In this way activity could be linked to money with reports on performance against targets made to the Council every six months. We were later told that arrangements for resource transfer are now clear.

2.5.13 Mr Q, Director of Finance for Yshire Primary Care Trust, was also optimistic about the future arrangements for dealing with delayed discharges. He referred, in a letter to the Commission (11 January 2002), to the central collation of robust information about patients to the good working relationships between the Health and Local Authority at all levels. He stated that delayed discharges were a key priority for health and social work and that the Joint Management Forum (see paras 2.4.9-2.4.10) had agreed an appropriate action plan. Mr Q also referred to the establishment of community based ventures, such as the Intensive Care at Home scheme which would reduce admissions. However, he acknowledged that these schemes were of little benefit to the Psychiatry of Old Age patients who had different needs.

2.5.14 Mr Q also gave the Inquiry Team a copy of a letter dated 18 December 2001 from Mr McT, Chief Executive of NHS Yshire to the Chair of the Finance and Resources Committee. This referred to the Resource Transfer and Bridging Finance Protocol which had been finalised in January 2001 with the agreement of all the responsible health and local authority bodies.

2.5.15 This protocol describes resource transfer purposes and procedures and defines key terms. It refers to detailed implementation plans for the Health Board and Local Authority for each commissioned service. It also states that Health Board and Local Authority Social Work Department representatives will meet quarterly to monitor resource transfer expenditure against agreed plans and targets. However, there is no reference to systems for reporting to the most senior managers progress or failure in implementing plans and policies. We were subsequently told that resource transfer is now an integral part of the joint health and social care Revenue Budget and both funds and activity will be regularly monitored.

2.6 The Context of Social Work Services in Yshire

2.6.1 This Inquiry focuses on Mr C's care. However, in the course of our investigations we were given substantial amounts of information about the special circumstances prevailing in Yshire which it was said were associated with his lengthy and largely unnecessary stay in hospital. Those interviewed were all aware that Mr C was only one of many patients, with and without mental disorder, whose discharge from hospital to the community was delayed for lengthy periods.

2.6.2 As we have already noted, until January 2002, Yshire was a Scottish authority with one of the largest number of patients in mental health specialities whose discharge had been delayed. We therefore conclude this Statement of Fact by recording those matters which those we interviewed claimed were relevant to health and social care policy and practice in Yshire.

2.6.3 First, the age structure of the population means there will be a relatively high demand for health and social care for older people. In Yshire in mid-2000 around a fifth of the population was over pensionable age; Yshire, is therefore one of the Scottish authorities with the highest proportion of people over pensionable age. We were told that Yshire is an attractive retirement area and this, together with normal demographic trends, means that the population of older people is continuing to rise.

2.6.4 Yshire is a predominantly rural area which can affect the distribution of and accessibility to health and social care services. For example, in Mr C's case, we were told that there were suitable vacancies in nursing homes in rural areas which his son would not consider because he had no car and could not visit his father.

2.6.5 There are also patterns of health and social care provision which can interact to create a demand for certain services. We were told that between 1996 and 2001 many beds were lost through ward closures. While such measures can release funds for community based services they can also increase demands for these services numerically and in terms of the dependency needs of those who use them. However, the Accounts Commission (November 2001) showed that in 1999/2000 Yshire had one of the lowest investments in home care. Even though the percentage increase in expenditure between 1997/1998 and 1999/2000 had been 32 per cent the proportion of overall community care spend remained very low.

2.6.6 Not surprisingly in 2001 Yshire had a low percentage of clients receiving more than 10 hours domiciliary care per week. One authority provided more than ten hours care for over half its clients and twelve other authorities achieved this for over a fifth of their clientele. Yshire also had in 1999 a low number of domiciliary care hours per week per thousand of the population aged over 65. Furthermore, in Yshire only a very small proportion of those aged over 65 being helped by the Council received evening or overnight care. Even with significant increases in home care homes for older people in 2000/1 Yshire still had less than half the average rate of home care homes for older people. Nine authorities provided this care for over a fifth of their clients over 65.

2.6.7 This pattern of provision was reflected in the care assigned to Mr C. He received less than seven hours home care a week and no evening or overnight care. His son increasingly found it impossible to make the three or four daily visits he thought were necessary, particularly in the evening. During the assessment of Mr C, while he was in respite care and in Prince Hospital, there appears to have been no consideration at all of the feasibility of Mr C remaining at home with increased support. Given the pattern of home care available in Yshire this is not surprising.

2.6.8 The balance of residential and home care in Yshire is further influenced by the availability of beds in care homes. The rate of private residential home beds per thousand of the population aged over 75 in 1998 and 2001 was high compared with the Scottish average. The rates for beds in voluntary homes at the same periods were also much higher than the Scottish average. The nursing home rates were closer to the Scottish average of 71 and 65. Yshire has substantially lower rates for local authority residential homes.

2.6.9 The implications of such a pattern of care home places are twofold. It can, particularly given the lack of home based care, encourage a culture of dependence on care homes. We were told by the consultant that in such a context a nursing home placement becomes the first option thought about when it should be the last. It can also mean that, with such a comparatively large population of people in care, the local authority will be faced with a larger than average need to fund places in care homes for people whose private resources have fallen below the threshold when they are no longer responsible for their own fees. We were told by Mr L that such demands consume a substantial proportion of the budget for residential and nursing homes in Yshire, with seven or eight residents per month requiring local authority support which would otherwise have been used to fund placements for delayed discharge patients.

2.6.10 There was a lively awareness of all these factors amongst respondents. A key question is the extent to which managers have taken them into account in policy development. We consider this matter in the next section.

SECTION 3:

Section 3.1 Comments and Observations

The assessment of Mr C's needs

(i) Assessment in the Community

3.1.1 Mr C had received a careful assessment by Mr E, Community Psychiatric Nurse, of his ability to care for himself given his deteriorating memory. The observations and conclusions of this assessment were substantially reflected in the assessment carried out by Mr Y, Care Manager, in October 1998. Partly because of Mr C Junior's increasing stress and anxiety, and because of Mr C's vulnerability when he left home unsupervised, it was quickly concluded that he should have a period of respite care during which an assessment of his need for permanent care would be considered.

3.1.2 We think that an assessment by an occupational therapist before Mr C went into hospital would have usefully contributed to Mr C's care plan. Such an assessment could have commented, for example, on aids, adaptations and environmental modifications and on leisure and recreation activities which took account of his visual impairment and dementia and which could have reduced his vulnerability and enhanced his quality of life. It is possible that such interventions might have made it possible for Mr C to remain for a longer period in his own home. They would also have provided some support and reassurance for his family.

3.1.3 There appears to have been no systematic analysis during any assessment of the risks to which Mr C was exposed or exploration of how these could be managed. For example, there are references to the dangers of Mr C touching his hot cooker but no apparent consideration of installing alternative means of cooking or adaptations appropriate for Mr C's visual impairment. In 2001 the Commission commented in its report on the care of Mrs K[1] of how such failures to analyse risks carefully can contribute to placement decisions which may be unnecessarily restrictive. There is no reference in any of the reports, and we were not told during our meetings with respondents, of any consideration of the feasibility of an increased package of home care to try and maintain Mr C in his own home. Given the sparse resources for home care in Yshire at that time that is perhaps not surprising. However, despite Mr C's deteriorating memory, in many respects his abilities would, in another authority with a stronger tradition of home care, have made him a candidate for an intensive package of home care. When Mr C went to Prince Hospital he could wash and dress himself, had good mobility, ate well and was fully continent during the day. There are no reports of his resisting help at home. The Commission has had contact with many older people with problems and dependencies similar to those of Mr C who have remained in their homes for substantial periods before going into residential care or, for whom there has been intensive home care for a trial period.

3.1.4 We also note that in these assessments there is no record of Mr C's own views about his future. Interviewees did not refer to this matter either.

[1] Mental Welfare Commission (2001) - *Report of the Inquiry into the Care and Treatment of Mrs K*

(ii) Assessment of Mr C Junior's Needs

3.1.5 Mr C was clearly helped greatly by his son's visits three or four times a day but there appears to have been no consideration of the possibility of Social Work Services taking responsibility for some of these visits and so reducing the demands on Mr C Junior. Importantly Mr C Junior was not offered a carer's assessment which could have explored means of helping him in the support he wanted to give his father or whether any of Mr C's three other sons could have provided some help. A carer's assessment would also have provided an opportunity to explore in depth Mr C' Junior's wishes for his father's care and what realistic contribution he could make to this. We were told that initially Mr C Junior did not want his father to go into hospital. He then accepted this, perhaps because no realistic alternatives were suggested.

3.1.6 Although Mr C's admission to hospital relieved Mr C Junior of many responsibilities it also appears to have had some impact on their continuing relationship in that Mr C Junior paid infrequent visits to his father during the three years he was in hospital. There is a record of only one outing (Christmas Day 1998) for Mr C with his son despite his known enjoyment of such events. Ms O told us that Mr C had loved going on his bike, he loved the fresh air and that he was quite a family man and a sociable person. There are similar references in social work and nursing notes. Mr C told us that he found it difficult to take his father out because of his reduced mobility. There has also been one upsetting occasion when Mr C had soiled himself while on a car trip with his son.

3.1.7 We were given no clear account of why Mr C Junior, who had been so conscientious in his visits to his father when he was in his own home, seemed to have limited contact with him. It was supposed by nursing staff and Ms O that Mr C Junior found the hospital environment distressing and that he had been upset on one or two occasions when his father did not recognise him. We were told that when Mr C's placement at Hilltop was being reviewed that he recognised his son for the first time for a long period. This is said to have made Mr C Junior quite emotional.

3.1.8 We were told of no attempts to discuss with Mr C Junior his own feelings about his father's dementia and care arrangement or to help him come to terms with changed behaviour and a different relationship. Equally there t were no concerted efforts to consider with Mr C Junior nursing home arrangements for his father which would have meant a speedier exit from Prince Hospital. There is no record of help and advice given when his father was leaving Prince and settling into Hilltop. There appears to have been no sustained discussion which might have helped Mr C Junior increase his visits to his father. In effect, Social Work Services had no working contact with Mr C Junior after his father went into hospital, apart from enquiries relating to financial matters.

3.1.9 Mr C Junior told us that he had greatly appreciated the help given by Mr E, his father's CPN. He gave him substantial support and advice while his father was still at home and particularly during the period leading up to Mr C's admission to hospital. After that Mr C Junior said he had no significant contact with Social Work Services or with any single care professional. He knew Ms O was his father's care manager but said his contact with her had only been about financial matters. From the

questions Mr C Junior asked us in our meeting with him it was clear that it would have been helpful for him to have had more advice and information about his father's illness, about possible treatment approaches and support services, about appropriate nursing home care and his continuing role in his father's care. As it was Mr C Junior said he felt "at the mercy of professionals" in their decisions and quite unsure whether any criticisms he had were justified. Mr C Junior also said he had found his father's steady deterioration most upsetting but, after his contacts with Mr E, there seems to have been no-one who offered him the chance to discuss such matters. Mr C Junior told us he had been given no guidance about ways of communicating with people with dementia or activities with which they could be involved. In short, after Mr C was admitted to hospital it seems to have been assumed his family would need no further help from Social Work Services.

3.1.10 The Guidelines on Assessment and Care Management (Social Services Inspectorate 1991) make a number of specific references to carers and carers' assessments. In the section *Enabling Partnership with Users and Carers*, (page 16), the Guidance states that the contribution of carers should be formally recognised in new procedures for care management and assessment. Carers may have community care needs in their own right and, if necessary, carers should be offered a separate assessment. The Carers (Recognition and Services) Act 1995, which came into operation in 1996, was the first time in British legislative history where carers were recognised as having needs of their own, with local authorities having a duty to offer carers an assessment of their own needs when those they care for are receiving their own community care assessment. Carers' rights have recently been strengthened in the Community Care and Health Act (Scotland) 2002. Although two periods of respite care were arranged to assist Mr C Junior we think the help offered to Mr C Junior in relation to his own needs was inadequate and is likely to have reduced the continuing contribution he could have made to his father's care.

(iii) <u>Assessment and Review in East House and Prince Hospital</u>

3.1.11 The review carried out in East House in December 1998 noted that the home was not coping with Mr C's disturbed behaviour, although it was also observed that the disturbance in his functioning was probably the consequence of the unfamiliar environment. At this point Mr C, who had already been perceived as a gentle and responsive man, began to be described as aggressive. He was grumpy and difficult and on one occasion had bruised the arm of a care assistant. This led swiftly to his admission to hospital where we were told his aggression was much less than expected given the reports that had been made of his behaviour. In the medical and nursing notes there continue to be references to Mr C's aggression, accompanied by comments that he was "no management problem". We think that a description which was partially accurate in December 1998 later became a rather carelessly used label. East House is not a specialist EMI Unit and not all staff would have had training and experience in working with people with dementia. It was suggested to us that Mr C's care would have been easier to manage if there had been advice on his management from a dementia specialist. Alternatively, specialist respite care, with staff who had more experience of working with people with dementia, might have provided an appropriate placement. In the event Mr C was transferred quite swiftly to Prince Hospital where he settled quickly. Three months later it was decided, apparently

without any serious consideration of alternatives, that Mr C should go to a nursing home with an elderly, mentally infirm unit (see para 2.1.15).

3.1.12 In the space of six months decisions had been taken which had the unintended consequence of Mr C staying in hospital unnecessarily for a further two and a half years. A lengthy stay in hospital could in part have been foreseen given the knowledge of numbers of delayed discharged patients, the lack of funding for community care placements and the long waiting list for Hilltop Home. Several people told us of the serious risks of deterioration for people remaining in long stay wards but this issue does not appear to have been considered specifically in relation to Mr C. Although as it turned out Mr C did not suffer in this way it was a risk that should have been acknowledged. We think there should have been consideration of these factors when Mr C's needs were being assessed and decisions made about his future. Dr C told us that in the light of experience with Mr C and other delayed discharges for patients who had been admitted for assessment he would be very reluctant to admit such people to hospital. He would try to resolve their problems at home although he did not think this was best practice in all cases.

3.1.13 Dr D told us that some years ago it had been possible to use admission to hospital as part of the process for maintaining people in the community. People could be assessed and stabilised and return home. In 1994, 75 per cent of such patients would return to the place they came from. Now consultants are reluctant to bring people into hospital for an assessment because there are unlikely to be any care home beds to enable their discharge if they could not return to their own homes.

3.1.14 After Mr C was admitted to Short Ward there was a full assessment of his medical and nursing needs. This commented on Mr C's capacities as well as his disabilities and on the need for these to be maintained through occupational therapy for which Mr C was assessed.

3.1.15 The nursing assessment and reviews during the rest of Mr C's stay in Prince Hospital record his physical needs and comment briefly on his behaviour which was generally regarded as unproblematic.

3.1.16 There were two medical reviews which are extremely brief, commenting that Mr C is waiting for funds for a nursing home place. One consultant remarked that there is a limit to the number of times 'no change' notes are meaningful. There were no medical notes for 16 months – October 1999 to February 2001. Increasingly the medical notes, where they exist, referred to Mr C simply as a "bed blocker". We were told that patients' reviews would be undertaken by the consultant and charge nurse. There was no other multidisciplinary involvement.

3.1.17 There were two reviews undertaken by Ms O in July 2000 and June 2001. There is no record of any other person being involved in these reviews. The only reference to a multidisciplinary review was to the one carried out in March 1999 which involved the consultant, Dr C, the Care Manager Mr Williams and Mr C Junior.

3.1.18 There is no record in any notes, and we were not told by any respondents, that reviews were seen as an opportunity to try and move forward plans for Mr C's care. All those we spoke to seemed resigned, almost fatalistic, about long waits for community

placements. We were told that staff had stopped telephoning the Social Work Department about delayed discharges because "they would have been on the phone all the time". No-one seemed to think that anything could be done to speed the process for a particular individual, although there were varying degrees of enthusiasm for plans to improve the system. This impotence and resignation – sometimes angry, sometimes depressed – were striking.

3.1.19 Ms O was Mr C's care manager. The Guidelines on Assessment and Care Management (1991) referred to in para 3.1.9, state that two core tasks are care planning and monitoring. Care management stresses the proactive contribution of monitoring in supporting the achievement of set objectives. It should also provide early warning of difficulties that might trigger a review before the one scheduled. We think that after Mr C had been assessed as requiring nursing home care these care management tasks were not adequately carried out.

3.2 Mr C's Care and Treatment

Medical and Nursing Needs

3.2.1 Mr C needed very little medical treatment. From time to time he received small doses of medication to settle his agitation. He had very few and only minor physical illnesses. There are several references to him being a fit and healthy man. We were told that "he had not been a particularly remarkable patient from a psychiatric point of view…. He was just a chap who was there".

3.2.2 The nursing notes make regular observations about Mr C's general state of health with the only recurring concern being his urinary incontinence. On admission Mr C was continent during the day but incontinent at night. Waterlow scales were carried out regularly to determine the risk of his developing pressure sores. Appropriate care was taken to ensure Mr C had incontinence aids to help preserve his dignity. There was also appropriate attention given to urinary tract infections. There are a few references in the medical and nursing notes to probable prostate problems including a medical note dated 15 September 1999 "continues with prostate problems", "enlarged prostate" (20 January 2000) and "? Prostate problems" (20 March 2000). There is no information in the medical or nursing notes to suggest that referral to a specialist was considered.

3.2.3 Mr C did not present any major challenges to the nurses; indeed from many comments made by those we interviewed it is clear he was well liked as a jovial and pleasant man. It was more possible to converse with him and establish a relationship than it was with other patients in the continuing care ward who were either bed bound or extremely dependent.

3.2.4 This positive response to Mr C's capacities probably contributed substantially to their maintenance. It would certainly have enhanced Mr C's quality of life in an environment which, despite the best efforts of nurses, was bleak and unstimulating.

Visual Impairment

3.2.5 In Yshire the specialist services for visually impaired people provide advice, information and mobility training for individuals with a visual impairment, and their carers. The service also provides awareness training on visual impairment to nursing and social care staff and has provided training at Prince Hospital. There is no record of any assessment by an occupational therapist of adaptations to Mr C's house or equipment which would have made it easier for him to manage at home despite his visual impairment. There is also no record after Mr C went into hospital of consultation with an occupational therapist about appropriate interventions to take account of limited vision.

3.2.6 Mr C was registered blind due to macular degeneration of the retina. An individual with this disease will have some but often limited peripheral vision, but will be unable to see detail, faces or colours. They will never go blind entirely but there will be a gradual deterioration over a five to six year period.

3.2.7 When Mr C was diagnosed as suffering from macular degeneration by an ophthalmologist, he was referred to the specialist service for visually impaired people who assessed his needs. He was provided with a white cane and attended a social club for people with a visual impairment. Studies of people over 65 with a visual impairment have highlighted isolation as a key area of concern. Mr C said his father much enjoyed this social club.

3.2.8 Once he was admitted to hospital, the specialist service for visually impaired people did not have any further involvement with Mr C, although he remained on their register. The Prince occupational therapy manager told us that for specific activities, the occupational therapist would probably refer someone to the specialist service for advice. When Mr C was in the admission unit, when occupational therapy was part of the multidisciplinary team assessing his needs, no referral was made to the service and no low vision aids were considered. The importance of the physical environment in the ward (especially lighting) was also not considered in any of the assessments. There was also no reference in medical and nursing notes that Mr C may require a regular return to the eye clinic.

3.2.9 Overall, there seems to have been a lack of knowledge and skill and perhaps concern, necessary to take proper account of Mr C's visual impairment. There are frequent references to this not presenting problems for Mr C. We think these are surprising since we were also told that Mr C could not read or join in games because of his limited vision. More attention to this impairment could have improved his quality of life.

3.2.10 We are also concerned that there appears to have been no occupational therapy contribution to plans for Mr C when he went to Hilltop Nursing Home. Occupational therapists can give much practical help and advice regarding the care of visually impaired people.

Activities

3.2.11 In the continuing care wards there was no regular occupational therapy or physiotherapy input and so virtually no activities or outings for patients. Nurses told us that they would like to have organised such events, including such modest activities as hairdressing and makeup sessions. However, they could not do so with any regularity because of their limited resources. We were impressed by the efforts of one named nurse who had brought his small children and pets to the ward on one or two occasions. They had engaged well with the patients who had responded positively to this contact. We were glad to learn that arrangements have now been made for pets to come regularly to the ward.

3.2.12 Charge nurses told us that they had made repeated requests for occupational and physiotherapy services but without success. We were told frequently that "continuing care is the bottom of the heap for resources". There had been plans to appoint an Activities Nurse but this person soon went on sick leave. There were also doubts about whether such a nurse would have been able to devote time to activities given the other nursing demands on the ward.

3.2.13 Given this situation it is not surprising there was no formal assessment of activities that would have been appropriate for Mr C. No patients on continuing care wards received such assessments. That such activities could be provided was made clear by Ms U, Superintendent Physiotherapist, who told us of the core skills and physical abilities that could be maintained through music, movement, and games. Visual and tactile activities were also important for people with sensory impairment. However, there were completely inadequate physiotherapy resources to provide a service to continuing care wards and, from early in 2001, to the assessment ward as well. Similarly there was no regular occupational therapy for continuing care wards and the daily input to Short Ward was withdrawn in 2000.

3.2.14 We were told by Ms U and Ms T, Head of Occupational Therapy, about the interaction between physiotherapy and occupational therapy in providing activities for older patients which would maintain their health and improve their quality of life. It is by no means the case, as some people assume, that for people with severe dementia there is no point in, or possibility of, providing regular activities. This is disputed by the Audit Commission's review of dementia services in England and Wales.[2] The Activities Guides published by the Dementia Services Development Centre,[3] as well as the evidence of experienced professionals proves that there are many worthwhile and stimulating activities for people with dementia. However, knowledge about these resources and commitment to improve the quality of life of patients in continuing care wards have to be matched by resources.

3.2.15 The Commission took a special interest in activities for patients during its visiting programme for 2001-2. We are aware of some grave deficiencies in the provision of appropriate and meaningful occupations for patients in hospital. This is particularly the case in continuing care wards where it is rare to find regular occupational and physiotherapy services. It is also rare for nurses or volunteers to be able to provide regular activities for these patients, most of whom therefore spend every day for the rest of their life with nothing to do apart from walking the corridors, if they are mobile, or watching television. Mr C is frequently recorded as walking up and down the corridors and occasionally trying the doors to get out. Interviewees told us that Mr C was "the only mobile patient and free to wander. That was how he filled his day". He was also "overactive at times – going up and down the corridor a lot". Mr C was a fit man, used to exercise and fresh air. Confinement in a ward for three years was therefore highly inappropriate. It was also likely to have been the source of major frustration for him, although there are no records of Mr C being asked about such matters, no doubt because little could have been done if he had expressed unhappiness with his daily routine. It is possible that frustration with his confinement may have contributed to Mr C's occasional aggressive behaviour.

3.2.16 When considering the regime of many continuing care wards, including those Mr C occupied while he was in Prince Hospital, it is instructive to remember contemporary criticism of the regime of the workhouses and asylums of the 19th century. The routines of hard labour, silence and discipline are shocking to us now. It is therefore

[2] Audit Commission (2000) *Forget Me Not Mental Health Services for Older People* (pp50-51)
[3] Carole Archibald (1990, 1003, 1999) *Activities 1, 11 and 111I*
Heather Hill (2001) *Invitation to the Dance*
Claire Craig (2002) *Celebrating the Person – a practical approach to art activities + Activity Pack*
All published by the Dementia Services Development Centre University of Stirling

worth asking whether the very different world of many continuing care wards today, with their empty days and capacity only to care, with kindness, for the physical needs of patients, will seem equally shocking some decades ahead. It is not surprising that some families find it difficult to visit their relatives in such an environment. It was particularly inappropriate for Mr C given his good health and relatively high levels of capacity.

3.2.17 In making these observations we wish to make it clear we are criticising the politics and management systems which allow such environments to continue. We are not criticising the nursing staff who cared for Mr C. For them he remained an individual about whom they frequently expressed concern. There was an attempt to get him a place in a day hospital so that his days would be more fulfilling. It was also nurses who raised concerns about Mr C's lack of finances and clothes and, with determination, tried to resolve these problems. These were matters which should also have been pursued by Mr C's Care Manager, Ms O. When, belatedly, they were brought to her attention she took appropriate action. Unfortunately, because there is no routine social work presence on continuing care wards nurses told us it would not have occurred to them to consult social workers about these problems. Nurses felt they were largely on their own and what needed to be done for patients would have to be done by them.

3.2.18 Some changes are taking place. We were glad to hear that South Ward had received some additional resources, including a Snoozelen room. It was also encouraging to be told by continuing care nurses that in the last 12 months there had been more training available for them. This would help them feel more in the mainstream of nursing care. However, it remains the case that when Mr C was in Prince its continuing care wards, like many throughout Scotland, did not appear to have the resources to provide an adequate quality of life for their patients.

3.2.19 However, we note that ISD data on Scottish Health Service Costs for geriatric psychiatric wards in 1999 record the total allocated cost for an inpatient week in Prince Hospital to be high compared with the Scottish average. It has been suggested that this relatively high cost is associated with the Trust's plans to half the number of beds in psychogeriatric wards.

3.3 The Management of Mr C's Funds

3.3.1 Very soon after his admission to hospital Mr C signed a Power of Attorney. It seems highly unlikely that he had the capacity to do this and we have noted that concerns were raised by nursing and medical staff. However, although it was known who the solicitor was who visited Mr C no attempt was made to enquire about the purpose of his visit or its outcome. It was assumed that the solicitor would contact the hospital if there was any question of Mr C signing a Power of Attorney. In the absence of further contact from the solicitor we think the consultant should have made further enquiries.

3.3.2 It is generally accepted practice for solicitors to contact the appropriate nursing and medical staff if there is some question about a person's capacity to sign a Power of Attorney. Such questions should certainly be raised about a patient who is in an acute psychogeriatric admission ward. It is also the case that the Scottish Executive Circular CCD2/1/1999 *Protection of the finances and other property of people incapable of managing their own affairs* states (paragraph 2.11) "Hospital managers should ensure that ward notices and admission leaflets state that relatives or solicitors seeking to conduct business matters with a patient should check the appropriateness of this with the senior nurse on duty". We do not know if in 1998 such information was available in ward notices and leaflets. Prince Hospital should take steps to ensure that this information is now displayed in ward notices and in leaflets.

3.3.3 Mr C was not declared Incapax until 7 July 2000. We were told that patients on the acute assessment wards were not routinely assessed regarding their capacity to manage their finances because it was assumed that most of them would not be there long. Incapacity assessments would, however, be routinely made for patients on long stay wards. However, nearly a year passed after Mr C moved to a continuing care ward before he was assessed as Incapax. Two months later, with Mr C Junior's consent a hospital account was opened for Mr C by the Patient Affairs Office. In March 2001 Mr C's retirement pension book was received in the Cash Office after Mr C Junior had relinquished his appointeeship in favour of the hospital.

3.3.4 From 5 January 1999 until 30 March 2001, a period of over 2 years, Mr C Junior, as his father's attorney, would have received his benefits on his behalf. We estimate these would have amounted to approximately £2,000. We have also noted (paragraph 2.2.10) that while Mr C was in hospital his savings of over £5,000 had been reduced to £76.

3.3.5 Ms O has told us that when she became aware of the depletion of Mr C's capital she sought advice from her supervisor and the Council's legal services about the appropriate course of action. We have earlier indicated (paragraphs 2.2.13-2.2.15) some confusion about the exact sequence of actions taken by Ms O.

3.3.6 While we recognise that, as his father's attorney, Mr C Junior was responsible for his father's funds we think enquiries should have been made about the depletion of Mr C's capital. Ms O did not want to do this because she was anxious not to damage her relationship with Mr C Junior. We have noted in paras 2.2.13 and 2.2.16 the advice given by Ms McP, the Council's Solicitor, that Mr C Junior should be asked about the depletion of his father's funds. We think such enquiries should have been made.

3.3.7 We also think that before advising the Council to discharge Mr C's accounts Ms O should have made some enquiries about the bills Mr C Junior said he could not pay. She should also have consulted the financial records to see if it was likely that Mr C would have had sufficient funds to meet these bills.

3.3.8 We note that when Ms O was informed about the difficulties in obtaining funds for clothes for Mr C she followed this matter up with his son and set in motion with him, the hospital and the Benefits Agency appropriate mechanisms for dealing with Mr C's financial and clothing needs. We think that ward staff should have involved Ms O earlier with these problems.

3.4 Arrangements for Dealing with Delayed Discharge Patients

3.4.1 Until June 2001, when the Funding Panel was established, there was no systematic method for prioritising community care placements for patients whose discharge had been delayed. The rule that available funding and vacant places had to match meant that there could be no predictable timing for an individual's placement. However, it was recognised that when a popular nursing home had been chosen, which had a substantial waiting list, there would be a long delay before the individual could be discharged. Surprisingly, until the summer of 2001, there appears to have been no attempt to try and deal with this situation by devising a local authority and Trust policy regarding choice of placements. There was also no sustained attempt to review with Mr C Junior whether his father's needs could have been properly met in a home other than Hilltop, or to discuss whether an alternative nursing home could provide a better quality of care than that available in Prince continuing care wards.

3.4.2 Consultants and managers with whom we discussed this matter said it was up to the Scottish Executive to give guidance about choice; and the Executive had declined to do this. There were no references to the Scottish Office Circulars SWSG 5/93 and SWSG 10/1998. The first emphasises the importance of individuals' freedom of choice in deciding their care. The second, written five years later, is more cautious and states "If the residential or nursing home of the older person's choice is unlikely to be available in the near future (8 weeks) the care manager should discuss acceptable alternatives with them. Health and social work agencies should consider the realistic personal and financial costs of this in discussion with the older person and their relatives. If the person is moving to long-stay care, one option might be to ask them to make a second choice of home, with the prospect of moving into the home of first choice in due course. Alternatively, the prospect of a temporary period of jointly commissioned intensive support at home to meet predictable needs should be considered".

3.4.3 We were also told by some interviewees that they would be extremely reluctant to put any pressure on individuals or families for other than a first choice of home to be accepted. Accepting other than a first choice could entail the disruption of further moves for a person should a first choice placement become available. Some interviewees also said they believed that people should not have to pay for nursing home care; there should be no added indignity of having to accept a second or third choice of home. When consultants or senior managers held these views it diminished any pressure there might be to move patients from hospital. However, some of those expressing these views also stated strongly that the delayed discharge problem had compromised their practice in that they could not now admit people to hospital who needed periods of assessment and care there. It would seem that adherence to strongly held principles can be barrier to maintaining preferred practice.

3.4.4 We have observed some reluctance on the part of many different bodies to engage with the question of whether patients' and relatives' choice of care home should be the determining factor in making a placement. We acknowledge the complexity of this issue, particularly in a climate in which all major political parties have attached great importance to citizens' choices. Choice is a central theme in most major government policy papers which deal with public sector services. However, we note that actual practice, for example in relation to parental choice of school or patients'

choice of hospital does not, indeed probably cannot, accord completely with policy intention and political rhetoric. We think that compromises may also have to be made in respect of choice of care home. We note some local authorities have already taken such steps; and in Yshire people are now asked to indicate second and third choices. A draft leaflet prepared by Yshire Health and Social Work bodies, dated September 2002, *Moving from Hospital to your Residential/Nursing* Home states 'It is much better to be in a homely environment such as a care home rather than stay in hospital. You will benefit from moving from a hospital to a care setting as soon as possible'. The leaflet then goes on to say that people are asked to make three choices because it may be necessary for them to move initially at least, to another care home which has a vacancy if the home of their first choice is full. We do not know how vigorously this policy will be pursued. A further Scottish Executive Guidance paper on principles and good practice in this area would be a valuable addition to those referred to in para 3.4.2.

3.4.5 Although the problem of delayed discharge and its causes were certainly recognised we observed the weary impotence about resolving these issues. There were frequent references to the responsibility, especially the financial responsibility of central government. Nurses and care managers felt that such matters were out of their hands and that nothing could be achieved by trying to speed up Mr C's discharge: indeed there was no system or person who could do this. Consultants felt either resigned to or impotent in the face of a situation which they thought could only be resolved with clear and firm local authority leadership, combined with major additional resources. They saw no likelihood of either. They also said they felt isolated from the arenas where important polices were decided. This thinking perhaps accounted for Dr C's apparently uncomplaining – or resigned – acceptance in March 2000 of Mr C's stay in South Ward when funding for his nursing home placement could not be used because there was no vacancy in Hilltop.

3.4.6 When the Commission raised the matter of delayed discharges at its 1999/2000 end of year meeting with Yshire Social Work Department this feeling of impotent resignation was also evident. We were told the Council had about 100 people waiting for community care funding. The particular patient about whom we were enquiring, who had been in an acute assessment ward for over twelve months, was not at the top of the waiting list and there could be no guarantee about when he would receive a place. First an occupied nursing home bed would have to become vacant; second, there would have to be no competition from a more urgent case. We were not told that there had been no funds to place hospital patients for the preceding year.

3.4.7 In 2000 there had been conferences and meetings between health and local authority staff to review the problem of delayed discharges. In these events much emphasis was given to the benefits that would result from the reconfiguration and strengthening of community care assessment and support services which would prevent people with lesser degrees of dependency entering hospital, and which would also enable their discharge from hospital to an intensive supported home. Some steps in this direction have been taken, as SHAS recognised in its positive reports of some aspects of older people services in Yshire and of old age psychiatric services in the Board area.

3.4.8 These welcome steps would not, however, reduce the number of people in hospital waiting to be discharged. It was not until June 2001, with the establishment of the

Funding Panel that any direct action was taken to deal with the substantial number of patients waiting for community care placements. We have already noted (paras2.4.9-2.4.10) that the Action Plan which had prompted the establishment of the Funding Panel was reviewed in August 2001 and revised (as a *Draft Action Plan*) in December of that year. We have also noted (see para 2.3.11) that some modest reductions in numbers of delayed discharge patients in mental health specialties have been achieved. We know that there have been changes made in the processes of the Funding Panel. We hope that these changes will mean a speedier and more substantial reduction in the numbers of delayed discharge patients in Yshire.

3.4.9 We observe that there remains much to be done, and not just in Yshire but Scotland as a whole. We were told that there were significant differences in the dependency levels of older people in care homes and hospitals in England and Scotland. Those in Scotland have lower mean dependency levels which suggests that community care services and care homes in England are more able to support older people with high dependency than are Scottish provisions.[4] We think it would be helpful for both health and social work services throughout Yshire to use a standardised measure of dependency at both assessment and review of older people. This will assist both appropriate placements and comparison of the scope and effectiveness of services.

[4] Audit Commission (2000) *Forget Me Not Mental Health Services for Older People*
ISD (2000-2002) *SHRUGS 1 & 2 Scottish Health Resource Utilisation Groups*

3.5 The Organisational and Managerial Context of Mr C's Care

3.5.1 Given the widespread awareness of the acute problems of delayed discharge we were very surprised that during the three years Mr C was in hospital no concerted managerial action (as opposed to debate and the preparation of papers) was taken to deal directly with this matter. We believe that in part this was because much of the time and energy of senior managers in Yshire, particularly in the local authority, were spent on the reorganisation of community services.

3.5.2 We had assumed before the Inquiry began that this new arrangement would have had direct implications for the management of Mr C's care. However, we learnt that it did not become operational until February 2002, some months after Mr C left hospital.

3.5.3 The admirable objective to provide completely integrated health and social care for the residents of Yshire required major reorganisation of services including funding, management and personnel arrangements. This complex planning was taking place, as we have noted in paras 2.4.1-2.4.3, while other major changes were being made in local authority services. We believe these simultaneous major management changes and future planning may have had adverse consequences for Mr C and other Yshire patients whose discharge was delayed.

3.5.4 First, senior managers were preoccupied with the difficulties inherent in the day to day operation of social work services while these were being realigned within the Council. Such preoccupations appear to have made it difficult to attend to more strategic matters, such as devising effective policies to deal with delayed discharges. Second, and more positively, managers were planning services which would provide intensive domiciliary care. Such services would eventually improve community care in Yshire and begin, for example, to redress the hugely disproportionate resources available for care homes as opposed to domiciliary care (see paras 2.6.6-2.6.11). Some interviewees told us, however, that they thought that these preoccupations had caused some planning blight in the development of day to day social care policy and practice between 1999 and 2001.

3.5.5 It was extremely unfortunate for Mr C and his fellow patients that they were awaiting discharge when prior to June 2001, there was no effective system to prioritise placement, no individual who felt it would be fruitful to promote his cause and no senior managers who attended to contemporary pressing problems of delayed discharge as well as trying to plan a brighter future for the health and social care services for Mr C's successors. We realise that the Joint Future arrangements for community services will, if they are effective, resolve or reduce many of the problems that dogged Mr C's care arrangements and those of many other delayed discharge patients. We have already observed that some of the management changes which were instituted in the run-up to the full implementation of the joint arrangements appear to have contributed to a reduction in the number of delayed discharge patients. We have subsequently been told about other positive developments and we look forward to hearing about further achievements.

3.6 The Special Circumstances of Yshire

3.6.1 We have already recorded the views of many interviewees that there were special circumstances in Yshire which affected health and social care policy and practice and were associated with the high number of delayed discharge patients in that area.

3.6.2 We acknowledge that the high proportion of people over pensionable age in Yshire, the rurality of the area and its balance of care in terms of care home places and domiciliary care services are all significant matters requiring the attention of the Board, Trust and Local Authority. We have noted some increases in the homecare budget and frequently expressed intentions to improve radically the intensive support available for people whose dependency might otherwise require them to go into care or to hospital. However, we have also noted the plan (para 2.4.10) to increase substantially the number of nursing home beds in the area, a development which managers acknowledged was not national policy. We recognise that within the Yshire Board area a substantial number of patients are waiting to be discharged to nursing homes. However, we have serious reservations about a plan to increase care home beds which, after the two or three years it might take to establish these beds, would reduce the number of delayed discharge patients, but would have other undesirable consequences. Increasing the supply of care home places will also increase demand for them. It is also likely to diminish the resources available to develop home based care which, as we have noted in paras 2.6.6-2.6.10, is urgently needed in Yshire. We were glad to hear in September 2002 that "recently there has been a 42 per cent increase in the provision of homecare, demonstrating the commitment to community care and joint futures". Such increases will need to continue if Yshire is to achieve even the average level of home care provision in Scotland.

3.6.3 The Commission cannot analyse in any depth the similarities and differences of authorities which appear to manage more effectively the discharge of hospital patients to community care or the mechanisms they use to achieve this. We know there are a number of factors in this complex equation, including the availability of continuing care beds. However, we believe this is an important task which we hope Audit Scotland will undertake. Now that the Scottish Executive has a clear priority that the problem of delayed discharge should be resolved, and not just in the short term, examination of the characteristics, policies and practices of the more or less successful authorities would be timely and constructive. We confine ourselves here to some observations of situations which we think need further analysis. We note, for example, that all the authorities with the highest proportion of the population over pensionable age are predominately rural; all are therefore likely to share similar challenges about providing accessible services. However, there are also some authorities whose profiles are similar to that of Yshire but who do not have substantial numbers of delayed discharged patients.

3.6.4 For example, Hillshire is a rural authority with a very low number of delayed discharge patients. Its investment in homecare as a proportion of total community care spend is only slightly higher than that of Yshire but, unlike Yshire, its rate of nursing home beds per thousand of the population over 75 is low. By contrast Hillshire has a high rate of residential homes. It would be interesting to know whether these homes are able to care for people who elsewhere might be placed in nursing homes, or

whether Hillshire has a high rate of continuing care beds. Both factors could contribute to the authority's low number of delayed discharge patients.

3.6.5 Seashire and Mainshire, again rural authorities, both with medium levels of homecare spend and a high rate of nursing home beds, also have very few delayed discharge patients. It would be useful to know whether their home care services can support people whose dependency is substantial until they need a care home, but without requiring admission to hospital. Rockshire, however, which for some time has had a high number of delayed discharge patients, has like Yshire, a low investment in homecare and a high nursing home rate. Further analysis is required to determine whether these two factors combined are significantly related to high numbers of delayed discharges.

3.6.6 It would seem from these brief observations that some authorities with similar challenges to those facing Yshire can manage their community care in ways which do not result in substantial numbers of delayed discharge patients. We hope there can be a full and systematic analysis by Audit Scotland of the context of these different outcomes, including the management, policies and individual care practices which are associated with low numbers of delayed discharge patients.

3.6.7 On the basis of the brief comparisons we have made it does not appear inevitable that the special characteristics of Yshire would have had a negative influence on its high number of delayed discharge patients.

3.7 Hospital or Nursing Home?

3.7.1 It is sometimes suggested that there should be no concerns about potential deficiencies in the care of someone who remains in hospital because his or her discharge is delayed. It is argued that such a person is safe, warm and receiving at least basic nursing and medical care. How is this different from the care that person would receive in a nursing home? Might it not even be superior?

3.7.2 We discussed this matter in general terms, and in relation to Mr C with interviewees. The responses were mixed and sometimes reflected interviewees' backgrounds. Some doctors and nurses tended to see the strong points of hospital care, and some of these people had only rarely if ever visited a nursing home; those from other professions unanimously favoured care homes. As we have described in paragraph 2.1.42 Mr C Junior told us he preferred Prince to Hilltop although we are not sure he is fully aware of the latter's facilities.

3.7.3 We were surprised by the comment of one consultant that people with dementia as severe as Mr C's would be unaware of subtleties of their environment and therefore it did not matter where they were. However, all other interviewees could comment on the differences in the environment and regime they thought would be important for people with dementia.

3.7.4 The strength of hospital care was said to include more permanent and better trained staff than would be found in nursing homes. Medical care would, of course, be more focused and, in particular, medication would be regularly reviewed with the aim of achieving the minimal of dosage required. Nursing homes were criticised for failures to review medication regularly, for over sedating residents and for the variable quality of care available from GPs. It was also said that many of their staff were young, untrained or poorly trained and transient.

3.7.5 Criticisms of long stay hospital care included disturbing environments in some wards with frequent arrivals of new and often very disturbed patients. The surroundings could often be bleak and institutional with poorly designed wards offering little chance of personal privacy. Care homes could be far less formal and more homely; individuals' own rooms could be personalised. It was also said that care homes are likely to provide a fuller social life for residents, with more activities and outings. We are aware that the quality of environment and care in care homes varies, as these do in continuing care wards. However, the recent publication of the National Care Standards for Homes for Older People sets the context for these expectations to be met and for highly individual care to be given. Care homes will also be inspected against these standards twice a year by the Scottish Commission for the Regulation of Care. There are no similar national standards for psychogeriatric assessment or continuing care wards although the Scottish Hospital Advisory Service Assessment Framework/Quality Indicators published in July 2001 will now provide a helpful context for staff and management to review the quality of care provided for patients in continuing care wards.

3.7.6 When speaking of Mr C virtually all respondents were clear that his needs would overall be better met in a care home. He did not need a high level of medical and

nursing care but he did need more activities and stimulation. He would be better off with people whose capacity was similar to his or higher.

3.7.7 We strongly agree with these views. We have already described what could not be or was not provided for Mr C in Prince and how his needs had been far better met in Hilltop Nursing Home.

3.7.8 All those responsible for the care of patients whose discharge is delayed should keep to the forefront of their concerns the needs of these individuals. Meeting these is the priority. Delayed discharge affects individual people and their families. It is not simply a question of bed blocking or inappropriate and uneconomic use of resources. In April 2002 ISD recorded there were 283 patients in mental health specialties in Scotland whose discharge was delayed. We agree completely with Trevor Jones' statement in his report to the Minister for Health and Community Care Delayed Discharges in Scotland (March 2002, p8):

'It is vital that the problem is not just seen as one of beds, budgets and statistics. It is the human dimension to this that must be at the forefront of action…. People are involved - more often than not admitted to hospital as an emergency because of a sudden illness or injury, with all the trauma and anxiety that brings. Then, when they are well and able enough to leave, they cannot. They are stuck in hospital waiting too long to be discharged to a more appropriate setting. Losing their independence, at risk of other infections, and in a hospital ward, which does not offer the comfort, privacy or quality of life that all of us want and need'.

SECTION 4:

Section 4.1 Summary of Findings

The Inquiry Team found that after his assessment Mr C then spent a further two and a half years in hospital, mostly in continuing care wards. Mr C had no medical need to be in hospital. Although his nursing care helped maintain Mr C in good health the hospital did not meet his social needs and Mr C's quality of life was extremely limited. There were no regular activities for him and nurses, although aware of this deficiency could not remedy it within the resources available to them.

After Mr C was admitted to hospital Mr C Junior received no significant help to meet his own needs or to assist him in making a continuing contribution to his father's care. For over two years there were difficulties in obtaining funds for Mr C's day to day needs. Whilst he was in hospital his capital was also depleted. The local authority made no formal enquiries into this matter.

Until June 2001 there was no systematic and effective method of prioritising community care placements and allocating funds accordingly. For over a year while Mr C was in hospital staff believed that a local authority manager would not permit community care placements for delayed discharge patients. In making placements patient and carer choice was emphasised. Community care placements could only be made if vacancies and funds were available simultaneously and there was no system that would ensure this. There was a general acceptance by those responsible for Mr C that nothing could be done to speed his placement.

While Mr C was in hospital there were major organisational and management changes in the Trust and the Council and also resulting from the plans to deliver community health and social care services jointly. The ensuing upheavals and uncertainties impeded the establishment of clear lines of responsibility for dealing with delayed discharged patients. Mr C was perceived simply as a bed blocker and, as an individual, he was lost from sight.

The Inquiry's detailed findings are as follows.

The Assessment and Review of Mr C's Needs

4.1.1 An occupational therapist did not contribute to Mr C's community care assessments prior to his hospital admission. There was no separate carer's assessment for Mr C Junior.

4.1.2 The assessment carried out in Prince Hospital did not appear to include any systematic analysis of alternatives to nursing home care. It also did not include any enquiry into Mr C's needs for occupational therapy or examine his visual impairment needs.

4.1.3 There were two medical and two social work reviews of Mr C's needs. None of these were carried out in any depth and it was simply accepted that he was waiting for a

nursing home place. These reviews, three of which were not multidisciplinary, were not taken as an opportunity to pursue this placement; nor did they consider the consequences of his remaining in hospital for an extended period.

4.1.4 There is no record of Mr C being asked his own views about his care.

Mr C's Care and Treatment

4.1.5 Mr C received adequate medical care although there was no investigation of the possible causes of his urinary incontinence.

4.1.6 Medical notes were mostly extremely brief and there were no notes for sixteen months (October 1999-February 2001).

4.1.7 Mr C's immediate care needs were met by nursing staff. Nurses spoke of Mr C positively and tried to resolve his need for money and clothing. Within the limited resources available to them there was little opportunity for nurses to improve significantly Mr C's quality of life.

4.1.8 Insufficient attention was paid to Mr C's visual impairment and its implications for his care.

4.1.9 After a brief period in Short Ward Mr C did not take part in any regular occupational or physiotherapy groups. There were no other activities provided for him.

4.1.10 Mr C was not declared Incapax until he had been in hospital for eighteen months. He signed a Power of Attorney shortly after he was admitted to Prince Hospital. Medical staff made no contact with the solicitor involved with this Power of Attorney about Mr C's capacity.

4.1.11 While Mr C was in hospital his son did not provide adequate regular funds for him. Mr C only received his retirement pension regularly after the hospital managers became his appointees in May 2001.

4.1.12 While Mr C was in hospital his savings of over £5,000 were reduced to virtually nothing. The Social Work Department made no formal enquiries into these matters.

4.1.13 After contributing to Mr C's multidisciplinary assessment in Prince Hospital there was little involvement from his care manager until she was asked to help with financial problems. Adequate assessments were made prior to Mr C's discharge from hospital and there was an appropriate review of his nursing home placement.

4.1.14 There was no social work presence on continuing care wards and no social work contribution to patients' reviews.

4.1.15 There was no regular occupational therapy or physiotherapy input to continuing care wards.

Community Care Arrangements

4.1.16 After Mr C had been assessed as needing a nursing home nobody took responsibility to hasten his placement. There was a general resignation that he would have to wait for a long time and nothing could be done to change this.

4.1.17 Until June 2001 a placement could only be made if funding and a preferred placement were available simultaneously. There was no effective system to ensure that this could happen.

4.1.18 On two occasions when funding was available for Mr C's placement there was no vacancy in the preferred nursing home. Those responsible for Mr C appeared to accept the situation.

4.1.19 There was no effective system whereby senior managers in either the Trust or Local Authority were routinely made aware of circumstances and delays affecting individual patients.

4.1.20 Mr C Junior's choice of nursing home for his father contributed to his lengthy stay in Prince. Attempts to discuss with Mr C Junior whether an alternative home would have suited his father's needs were not vigorously pursued..

4.1.21 Until June 2001 there was no effective system for reviewing and prioritising placements for delayed discharge patients and for matching funding with available placements.

4.1.22 Amongst staff there were different uses and understanding of financial terminology and confusion about the origins and composition of resource transfer. As a result there was a widespread perception that there were no, or only very limited funds, for community placements for delayed discharge patients.

4.1.23 There was a lack of clarity about the size and composition of community care budgets.

4.1.24 Reorganisation of Social Work Services within the Council, changes in management in the Trust and Board and the prolonged debates about the restructuring of health and social care services created long-term uncertainties for managers and staff. This contributed to the absence of effective policies to reduce the number of patients whose discharge was delayed. After the restructuring of the services was agreed there were reductions in these numbers.

SECTION 5:

Section 5.1 Recommendations

Scottish Executive

5.1.1 The Scottish Executive should issue further guidance on principles and good practice in accommodating individuals' and relatives' choice of nursing home in placement arrangements.

5.1.2 The Scottish Executive should issue guidance on the provision of occupational therapy services in the community and in hospitals.

5.1.3 Audit Scotland should be invited to review the policies and practices which are associated with Trusts and hospitals having high and low rates of delayed discharge patients.

5.1.4 There is a clear need for simplification in the financial terminology used throughout Scotland when dealing with community care funding and for a set of definitions agreed between Boards, Trusts and Local Authorities which can be fully understood by their staff. The Scottish Executive should ask the Scottish Health Directors Finance Group, in conjunction with their Local Authority counterparts, to produce such a clear set of definitions.

Yshire Primary Care Trust/Health Board

5.1.5 Senior managers must regularly review with their Local Authority colleagues delayed discharge patients both overall and on an individual basis.

5.1.6 Occupational and physiotherapy services should be regularly available to psychogeriatric wards and not simply individual referred patients by April 2003.

5.1.7 There should be evidence of consultation between occupational therapy, physiotherapy and social work managers and senior hospital managers with regard to the provision or withdrawal of specific services.

5.1.8 Where Allied Health Profession resources are finite there should be evidence of a system of priorities which takes account of the views of the multidisciplinary team, patients, relatives and carers.

5.1.9 There should be a review of the skills mix on wards with no provision of activities to consider the introduction of Occupational Therapy Assistance posts or Nursing Activity posts.

5.1.10 In conjunction with the occupational therapy manager the lead clinician should initiate and lead a working group that is needs led and whose purpose is to improve the quality of life of patients on wards with no Allied Health Professional input. It should be multidisciplinary and include patient/relative/carer representation, voluntary services, chaplaincy service and a representative from the finance department (endowments).

5.1.11 The Allied Health Professions should actively contribute to a multidisciplinary programme of continuing professional development on wards with no Allied Health Professions input.

5.1.12 There should be a clear expectation that there will be regular quarterly multidisciplinary reviews for patients on continuing care wards. These reviews should include consideration of care plans which will maximise patients' quality of life.

5.1.13 Ward notices and hospital leaflets should remind solicitors that they should consult medical staff where there is uncertainty about a patient's capacity to sign a legal document. Such leaflet should advise solicitors to consult the Law Society for further guidance. The Commission would like to receive copies of these notices and leaflets by 20 December 2002.

5.1.14 The Trust must ensure that the capacity of all patients in psychogeriatric wards should be assessed within four weeks of their admission. Capacity must also be regularly reviewed. Assessments and reviews should be multidisciplinary. Attention should be paid to the principles and recommendations of the Crosby Report, to the principles and provisions of the Adults with Incapacity Act 2000 and to its relevant Codes of Practice.[5]

Yshire Council

5.1.15 The Council must ensure that its most senior managers receive regular reports, at an individual level, of all patients whose discharge is delayed because they are awaiting access to community care resources.

5.1.16 Throughout the Council there must be an agreed system for assessing the dependency levels of people with dementia to assist appropriate placements.

5.1.17 Social Work Services should ensure that there are clear arrangements for carers' assessments and for the requirements of the relevant carers' legislation to be met. The Commission wishes to receive the Council's policy on this matter by 20 December 2002.

5.1.18 Social Work Services should review its guidance on reviewing and monitoring care management. The Commission would like to receive a copy by 20 December 2002.

5.1.19 The Council and the Trust must ensure by April 2003 that there is social work presence on all older people's wards.

Joint Future Group

5.1.20 The joint service must ensure that the Funding Panel which is responsible for community care placements has clear guidelines and criteria for its operation. The Commission would like to be informed of these by 20 December 2002.

[5] Scottish Home and Health Department (1985) *Report of the Working Party on Incapax Patient's Funds* HMSO

5.1.21 The managers of this joint service must be informed about every individual whose discharge is delayed for six months. There should be a review of this person's needs and recommendations made for further action. These systems should be in place by December 2002.

5.1.22 For the joint service to be effective it must ensure that the resources which provide intensive domiciliary support are readily available for people with dementia. The dependency levels of people using these services should be regularly monitored.