

**The Death of a man
at HMP Durham
on 19 November 2004**

**Report by the
Prisons and Probation Ombudsman
for England and Wales**

September 2005

This is the report of an investigation into the care afforded to a man at HMP Durham. He was 52 years old when he died on 19 November 2004. He had taken an informed decision to decline all clinical care pertaining to his kidney transplant on reception into prison. He wrote an Advance Directive (Living Will) with his solicitor outlining the care he did not wish to receive in the event of his health declining.

The Head of Primary Care Services at Durham and his team ensured that his wishes were met at all times. They did so in an exemplary manner with respect, dignity and compassion. His family were welcomed at Durham and afforded appropriate and sensitive support. On one occasion, arrangements were made for them to remain with the man throughout the night. The healthcare team led by the Head of Primary Care Services should be strongly commended for the way in which they managed all aspects of the man's care.

I wish to offer my sincere condolences to the man's sister, her partner and all those who knew him. I trust that comfort can be gained from the knowledge that at all times his wishes were adhered to.

The investigation has been led by a colleague on my behalf. I would like to thank the Governor and his staff for their participation in the investigation. The Prison Carestream Lead of Northumberland Care Trust undertook the Clinical Review and I am grateful for his comprehensive review.

The circumstances giving rise to this report were unusual. So too are the concluding words I have written on page 26 below: that the care provided for the man demonstrated a degree of decency I have rarely witnessed in over 25 years visiting and writing about prisons.

Stephen Shaw CBE
Prisons and Probation Ombudsman

September 2005

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SUMMARY

1. The man was received at HMP Durham on 17 February 2003. At that time, he was 50 years old and had no previous convictions. He was charged with the murder of a woman he had met in a public house in South Shields.
2. He had received a kidney transplant at a hospital in the Northeast in 1986.
3. When he was received at Durham he immediately indicated that he would no longer take the medication that prevented his body from rejecting the transplanted kidney. At the request of the Head of Primary Care Services at Durham, the man was seen on several occasions within days of his arrival by a Consultant Forensic Psychiatrist. The man told the psychiatrist that he was discontinuing his immuno-suppressant medication because his quality of life since the transplant had been poor and it was “a depressing existence with a bleak future”.
4. On 28 February 2003, the man drew up a Living Will in the presence of his solicitor. The Living Will stated he would no longer take any immuno-suppressant medication and he refused any medical or surgical treatment which was by way of kidney dialysis or further kidney transplant, and also any medical or surgical treatment if it would needlessly prolong his life or postpone the actual moment of his death. He consented to any treatment that would safeguard dignity or make him more comfortable or relieve pain and suffering.
5. In 2002, the Department of Health (DoH) published Seeking Consent, a set of guidelines for healthcare professionals working with people in prison. The document explicitly states that respect for people’s rights to determine what happens to their own bodies is a fundamental part of good clinical practice and also a legal requirement. In all their dealings with the man during the 21 months he spent at Durham until his death, the Head of Primary Care Services (the doctor) and his colleagues adhered meticulously to the requirements set out in the DoH document. The doctor had to be sure that the man had the capacity to take the decision to discontinue his medication. He also had to be certain that the man was acting voluntarily. The formal advice to the doctor from the Consultant Forensic Psychiatrist was that the man was in total possession of his faculties at the time he signed his Living Will and he knew what he was doing.
6. The man was sentenced to life imprisonment at Newcastle Crown Court on 5 March 2004 and, as the year progressed, his condition deteriorated. The doctor respected to the letter the requests made by the man in his Living Will, and indeed wrote to him in late June 2004 suggesting ways in which the wording of the document could be made still clearer.
7. The doctor endeavoured to obtain the very best possible clinical treatment for the man, and he communicated extremely clearly in writing with all his clinical colleagues at the

prison so that uncertainty about the complex ethical and human rights issues raised by the man's Living Will was reduced to a minimum.

8. The man died in the prison's Healthcare Centre (HCC) on the evening of 19 November 2004. The doctor formally considered the option of transferring him to an outside hospital in the last days of his life, but he was not convinced that there was any more that would be done in hospital than was being achieved in the prison.
9. I commissioned a Clinical Review in relation to the man's care from the Prison Carestream Lead at Northumberland Care Trust. He concludes his review by stating that the doctor and his team are to be complimented on their efforts to care for the man, whose management was complex and provided many ethical dilemmas for the clinical team.
10. The post-mortem report supplied to the Coroner gives the professional opinion that the cause of the man's death was chronic renal failure due to hypertension. The pathologist reported that "the fact that the man stopped taking his immuno-suppressant medication will have hastened the failure of his transplanted kidney".

THE INVESTIGATION PROCESS

11. The responsibility for investigating deaths in prison custody passed to the Prisons and Probation Ombudsman on 1 April 2004. The Ombudsman's responsibilities include the investigation of prison deaths from apparent natural causes.
12. The man died on 19 November 2004 whilst he was a serving prisoner at HMP Durham. He was sentenced to life imprisonment in March 2004 and my investigator received a very large number of documents relating to the man from HMP Durham. One of my Family Liaison Officers made contact with the man's sister. My investigator also spoke to her at a later date and he had lengthy conversations about the circumstances of the man's life and death with the Church of England Chaplain at HMP Durham, and with the doctor at the prison.
13. I commissioned a Clinical Review from the Northumberland Care Trust. Clinical services at HMP Durham are commissioned by Durham and Chester-le-Street Primary Care Trust (PCT) and the Northumberland Care Trust is completely independent from the PCT. The Clinical Review was undertaken by the Prison Carestream Lead at Northumberland Care Trust, and I am most grateful to him and his Trust for undertaking this work on my behalf.

INFORMATION ABOUT THE MAN

14. He was born on 11 June 1952 and at the time of his death was 52 years old. He had never been in prison before and was accused of the murder of a woman in South Shields. A very useful source of information about his life is a letter written on 7 March 2003 by the Consultant Forensic Psychiatrist to the doctor at Durham Prison.
15. In the letter, the psychiatrist explains that he had seen the man on three occasions since his reception at the prison. The man was seven years old when his father died. There were three boys and two girls in the family and he was the youngest child. He told the psychiatrist that he felt he was reasonably bright at school. He left school at 16 after passing five CSEs because he wanted to earn some money. He did, however, do some further study when on kidney dialysis in 1983. At that time he enrolled with Open University, studying for two and a half years and being halfway through his degree course at the time of a kidney transplant in 1986. He changed his degree course to study law and did two years of law studies, but then discontinued it for health reasons and because his marriage was failing.
16. In 1968, he started working for the Civil Service in a clerical capacity. In 1972, he transferred into shift work on Civil Service computers. Between 1968 and 1973, he worked in the Department of Health and Social Security (DHSS), as it was then known, then in 1973 he left to find alternative employment. He informed the psychiatrist that he felt he could not move on until his health problems were sorted out. He worked intermittently when able to do so as a clerical officer in the same DHSS office. He also ran a small business with his wife involving hairdressing. He tried to get back to work in 1996 but told the psychiatrist he was unable to cope.
17. He had married in 1975, when he was aged 23. His wife was two years younger and was a hair stylist. He told the psychiatrist that they decided not to have children as he knew he would have to go on dialysis and how difficult that would be. He also said that he had suffered suicidal depression following his kidney transplant. When interviewed for his Reception Health Screen at Durham at 17 February 2003, he told the nurse that he had suffered depression in 1987 and took an overdose of paracetamol and sleeping tablets. He told the psychiatrist that he felt the side effects of the steroids prescribed to him fractured the relationship with his wife. They started living apart but remained in the same house between November 1992 and October 1994, then the house was sold and they divorced.
18. Prior to his remand in prison, he was living on his own in a flat next to his sister who had supported him in the past and was to do so after his arrival in prison. He was in pain and unemployed. He enrolled on two courses, Higher Education Foundation Course in Law and a course in computers held on Tuesday and Friday afternoons. He had three close friends, whom he had known for over 30 years. He told the psychiatrist that he would see one of these friends every two or three weeks and, although he saw the other two less often, they kept in touch.

19. In relation to his medical history the psychiatrist wrote as follows:

"His past medical history also centres around his renal problems. Renal failure was diagnosed aged 22, this being in October 1974. He has had 20 or so operations for this. He has also been on dialysis, being on Haemodialysis for three years and on Peritoneal dialysis for seven years, making 10 years in total. His renal transplant took place on 28 July 1986. He made a good recovery from the surgery. He was put on high dose steroids. In August/September 1986 he lost confidence, his sleep and appetite became problematic and he apparently became depressed. He tried to commit suicide in January 1987, taking paracetamol, sleeping tablets and whisky. He thought he had taken enough to kill himself. He was alone in the house at the time. He said he came around and hadn't died. He rang his wife who told him to take a taxi to the hospital and there he told them what had happened."

20. Shortly after his arrival at Durham on 17 February 2003, he told the prison authorities that he would no longer take the immuno-suppressive medication that prevented his body from rejecting the transplanted organ. In his letter to the doctor of 28 February 2003, the psychiatrist reports the man as telling him that he stopped taking the immuno-suppressants just over a week previously. He told the psychiatrist that his quality of life since the transplant had been poor and that it was "a depressing existence, with a bleak future". He thought he might develop renal failure within weeks or months. The psychiatrist's letter continues:

"He did not regard this as being an act of suicide but one of 'refusing unnatural medication and letting nature take its course'."

THE MAN'S TIME AT HMP DURHAM

21. As already indicated, he had no previous convictions before his reception at Durham on 17 February 2003. He was charged with the murder of a woman at South Shields. On 5 March 2004, he was sentenced to life imprisonment at Newcastle Crown Court for that offence. In his sentencing remarks, the judge said that the man was of previous good character. He met the deceased at a public house in South Shields after he had consumed four pints. The judge said that the man arranged to leave the public house so that some sexual activity could take place with the deceased. They drove to a nearby car park where an argument began. The deceased woman caused considerable damage to his car and he pulled her out of the vehicle. He then drove his car straight at her and struck her. She struck the top of a brick wall and then fell to her death some 20 feet or so below.
22. A Multi-Agency Lifer Risk Assessment Panel took place on 7 May 2004. A number of participants at the panel meeting referred to the link that the man made between the drugs he was taking and the crime he committed. The home Probation Officer reported to the panel that he blamed the incident on the medication he was taking for his kidney transplant. The prison Probation Officer stated that the man thought his medication was to blame for the incident. The psychologist indicated that the man had told her that the steroids he took made him depressed. The man's Lifer Officer also reported that he blamed his medication for what had happened and he added:

"He blames his medication for all of his adverse behaviour; he says that it was after he started taking the medication that his behaviour changed."
23. Later in his contribution, the Lifer Officer added that the man had been on the medication since 1986.
24. On three occasions during his time at Durham, the man was on an open F2052SH (Self-Harm at Risk Form). The front cover of the form explains that it may be raised by any member of staff who is concerned about a prisoner and page 1 of the document states that "the purpose of this form is to ensure that as much help as possible is given to a prisoner during a difficult period when he may be at risk of self-harm or following self-harm."
25. The first F2052SH was opened in the cells at South Tyneside Magistrates' Court by the escorting staff who then transferred the man to HMP Durham. The Prisoner Custody Officer who opened the form wrote that she had done so because of the seriousness of the offence with which the man was charged. A F2052SH is reviewed at regular intervals and at the first review on 20 February 2003 the Charge Nurse, who chaired the review, wrote:

"The man stated that he made an informed decision long before coming into prison to refuse taking certain medications because of the side effects. He is aware that he may become ill or die as a result of this and has signed a medical disclaimer."

26. On 28 February 2003 the man signed an Advance Directive or Living Will in the presence of his solicitor. This Living Will is discussed in greater detail in a later section of this report.
27. On 20 March 2003, following a review it was decided to close the man's F2052SH. He was feeling fine and was recorded as stating he had no intention of self-harming and suicidal intentions had never been an issue.
28. He was located in the prison's HCC from his arrival on 17 February until 27 August 2003. He was therefore still in the HCC when a second F2052SH was opened on 1 April 2003. The document then remained open for four and a half months until 18 August 2003. The stated reason for opening the second Self-Harm at Risk Form was that he was refusing medication for specialised treatment. A Nurse's assessment on 1 April 2003 was that the man was fully aware of his situation and had no intention of physically self-harming. In a review soon after the second document was opened, it was reported that he did not feel the need for F2052SH to be open. He felt it was open only for political reasons.
29. Regular reviews of the F2052SH continued until 16 August 2003 when the review summary reported the man's view that everything was going well, and he still felt that F2052SH should be closed as he had no intention of physical self-harm. The review coordinator spoke two days later to the prison's Suicide Awareness Officer and it was decided to close the form, as there was no evidence of severe deterioration in the man's medical condition at that moment.
30. A Self-Harm at Risk Form was opened for the third and last time on 5 March 2004. On that date, the man had received his life sentence and a member of the Chaplaincy Team at the prison was sufficiently worried after speaking to him on his return from court to open the document. The prison authorities were understandably concerned that there might be a delayed reaction by the man to his life sentence and they were aware that he wished the form to be closed as soon as possible. The form was indeed closed just ten days later.
31. In terms of cell locations, he spent his first six months at Durham until 27 August 2003 in the HCC. He then had brief spells in normal residential accommodation on C Wing and E Wing before moving to A Wing on 28 September 2003. He remained on A Wing for nearly 10 months until 14 July 2004 when he was again returned to the HCC so that he could be given closer medical attention. He remained in the HCC from July until 19 November 2004, being in cell M2-5 from 3 September until the date of his death. Entries about him in his prison record were uniformly complimentary. On 25 May 2003, he was described as 'a model prisoner' who took part in all the activities in the HCC. On 9 August 2003, an entry by an Officer stated that he continued to give staff no cause for concern and that he helped his disabled cellmate with all tasks. For a long period of time, he had a job as orderly in the prison library. An entry on 4 September 2004, is as follows:

"The man appears to be quite supportive of other prisoners in the Health Care, often taking time to chat to them if they are having a problem."

32. He was a practising Roman Catholic and the Church of England Chaplain told my investigator that he always attended RC services until about two weeks before his death. She described him as a nice chap, who dealt with his illness bravely.

THE MAN'S MEDICAL TREATMENT WHILST AT DURHAM

33. A very helpful summary of the treatment he received is contained in the letter sent by the doctor at the prison to the Coroner for Durham after the man's death.
34. The doctor explained that the man had undergone renal transplantation in 1986 for renal failure secondary to hypertension. Prior to the transplant, he had undergone a long period of dialysis.
35. At around the time of his reception into HMP Durham, the man had taken the decision to stop the anti-rejection medication necessary to preserve the life of his transplanted kidney. The doctor saw the man at around this time, discussed his intentions and noted the contents of his Advance Directive. The Advance Directive made it clear that the man was not willing to accept any treatment for renal failure in terms of dialysis or further transplantation, but he was willing to accept such dietary and pharmacological help as was necessary to maintain him in good physical condition. He was aware that the inevitable consequences of his declining to take his anti-rejection medication would be renal failure and death. His intention was not to kill himself but simply to stop taking the medication and to live as best he could without it.
36. The doctor told the Coroner that the explanation to the man's approach lay in the facts that: (i) he felt that he had a very unhappy experience of dialysis; and (ii) that the medication given to him following his transplantation had induced a degree of depression and other psychological changes which he had found intolerable. The doctor believed that the man had been involved in litigation with the physicians who had looked after him at the time of his transplant and he clearly blamed them for what he felt were unacceptable side effects of his medication.
37. He discussed his intentions and the consequences of his actions on many occasions with the doctor. With the man's consent, the doctor sought advice from a Consultant Forensic Psychiatrist. The psychiatrist found the man, as did the doctor, to be of sound mind, fully competent and fully understanding of the consequences of his actions.
38. The man's kidney function, blood count, blood pressure and calcium levels were monitored over his remaining 18 months of life. The doctor was initially able to seek help with the man's management from the Consultant Renal Physician at a nearby hospital, but the man learned that one of her colleagues had once worked in the hospital where he had his kidney transplant and he declined to have any further input from that source. The doctor commenced the man on erythropoietin, a drug designed to try and maintain normal blood levels. Unfortunately he developed high blood pressure which is an accepted complication of the treatment and the doctor stopped this while his blood pressure was brought under control. The man's haemoglobin level fell quite dramatically and towards the end of his life he was transfused twice.
39. The doctor felt that the man's blood pressure in the last fortnight of his life was low enough for erythropoietin treatment to be recommenced because his view was that the

benefits outweighed the risks. In the last week of his life, the man developed severe back pain and the doctor sought the guidance of a Consultant in Palliative Medicine. She saw the man in a nearby hospital and in prison two days before his death. She provided guidance on his management during his last few days. His background pain control was through Fentanyl patches. Additionally, he had Fentanyl lozenges three times a day and Oramorph on an 'as and when' required basis. During her visit on 17 November, the Consultant in Palliative Medicine revised the man's prescription. He was determined to have reasonable pain relief with minimal clouding of consciousness and the doctor felt that his team had achieved this. Sadly, but inevitably, the man died on the evening of 19 November 2004.

THE MAN'S DEATH AND FOLLOWING EVENTS

40. The man's sister was a regular visitor to him during the 21 months he spent at Durham. In the last week of his life, he was in great pain. The doctor told my investigator that, on the evening of Tuesday 16 November 2004, he thought it advisable for the man's sister to be invited to visit again. The prison sent transport to collect her and her partner from their home in Newcastle. The man's continuous clinical record shows that at 9:15pm on 16 November his relatives arrived for a visit in his room. They were given refreshment. On more than one occasion, a Nurse wrote in the clinical record that he was shouting out in pain. At 11:30pm, she noted that the visitors were still present and that he was settled. At 0:30am on Wednesday 17 November, she noted that he was feeling tired and that his visitors were worried about leaving him. She invited his sister and her partner to rest in the ward and they were given refreshments. At 1:40am, the Nurse spoke to the man and gave him reassurance, then at 2:20am his relatives returned to sit with him. He was now awake and conversed with them. At 3:20am, he was settled and asleep with his relatives still present. At 6:15am, the Nurse recorded that his relatives had to return home. Over the next two days, his sister remained in telephone contact with the prison.
41. The last full night of his life was from Thursday 18 to Friday 19 November 2004. The Nurse meticulously made regular entries in his continuous clinical record throughout the night. Time and again throughout the night there is reference to making him comfortable and giving him reassurance. The level of care and compassion he received at this time is hugely impressive.
42. At 7:10pm on the evening of 19 November 2004 an entry was made in the continuous clinical record as follows:

"Has been asleep most of day; chesty rattle noted. Regular pain level checks carried out and analgesia offered but declined. Had visit this pm by sister and husband. They have been offered a further visit on Saturday a.m."
43. At 7:30pm the final entry before his death referred to rattly breathing. He appeared settled with the writer noting "we appear to be doing all we can for him". All the available evidence leads me to concur with this assessment by the nurse.
44. He declined to go into his bed as he wished to remain in his chair.
45. In a Witness Statement to the Governor, a Senior Officer reported that at approximately 7:30pm he took over watch duties in Cell M2-5. At approximately 8:40pm, he noticed that the man was not breathing. He shouted for the Nurse and Staff Nurse. At approximately 8:42pm, they entered the cell to check the man for signs of life. At approximately 8:45pm, the Senior Officer helped the Staff Nurse to move the man from his chair into his bed so that he could be examined more easily when the doctor arrived.

46. The Nurse's account to the Governor states that she was on duty as Healthcare Officer Night Duty on the evening of 19 November. The Senior Officer informed her that the man was unresponsive. The Staff Nurse and the Nurse attended and checked for vital signs. The man had no pulse and his eyes were fixed and dilated.
47. The prison's Medical Officer attended at 9:08pm and certified the man's death.
48. He had received the last rites prior to his death. The news that he had passed away was conveyed to his sister on the evening of 19 November by means of a telephone message from a member of the prison's Chaplaincy Team. The man had had very regular contact and conversations with members of the Chaplaincy Team throughout his time at Durham. He was a Roman Catholic but when he died there was no Catholic Chaplain in post at the prison. To her surprise and delight the Church of England Chaplain was invited by the family to conduct his funeral service at Newcastle Crematorium.
49. His sister told my Family Liaison Officer that she had to "chase the prison to get her brother's possessions back and there was also a long delay before she received a cheque for his money".

POST-MORTEM REPORT

50. After the man's death, a post-mortem was conducted on 23 November 2004 at the mortuary in a hospital near the prison. The pathologist was the Senior Lecturer in Forensic Pathology at the University of Newcastle-upon-Tyne and Home Office Pathologist for the North East of England. The Coroner has kindly made the pathologist's post-mortem report available to me. The pathologist reported to the Coroner that his opinion as to the cause of the man's death was chronic renal failure due to hypertension. At the conclusion of his report the pathologist wrote:

"It appears that the man died, as indicated clinically, from chronic renal failure due ultimately to the effects of hypertension. This hypertension had destroyed his native kidneys and led to the renal transplant operation in 1986. The fact that he stopped taking his immuno-suppressant medication will have hastened the failure of his transplanted kidney.

"Elsewhere the left ventricular hypertrophy is consistent with the effects of hypertension. Terminally, he had developed bronchial pneumonia, a common terminal complication of a large number of natural conditions including renal failure."

HMP DURHAM

51. Durham Prison opened in 1819 and was rebuilt in 1881. Since then it has maintained its primary role as a local prison serving courts in the North-East. The prison contains both remand and sentenced prisoners.
52. Her Majesty's Chief Inspector of Prisons made a full unannounced inspection of the prison in August 2003 and published her report in November 2003. She described Durham as:

"a very complex prison, holding Category A men and women (the highest security category), as well as operating as a local prison, and running a closed supervision centre for some of the most dangerous prisoners in the prison system."
53. The Chief Inspector observed that Durham was operating under great population pressure but the inspection found that, nevertheless, it was providing a fundamentally safe and decent environment.
54. Durham offers a range of healthcare facilities, including a 19 bed inpatient unit where the man was located at the time of his death. The prison has 24 hour qualified nursing care cover.

THE MAN'S LIVING WILL

55. The crucial issue in this case is the Living Will made by the man on 28 February 2003 and the response to that document by the doctor and his colleagues at Durham Prison. The man's Living Will was witnessed by his solicitor and states:

"I refuse any medical or surgical treatment which is by way of kidney dialysis or further kidney transplant and also any medical or surgical treatment if:

- Its burdens and risks outweigh its potential benefits; or*
- It involves any research or experimentation which is likely to be of little or no therapeutic value to me; or*
- It will needlessly prolong my life or postpone the actual moment of my death.*

I can consent to being fed orally and to any treatment that may:

- Safeguard my dignity; or*
- Make me more comfortable; or*
- Relieve pain and suffering;*
- Even though such treatment might unintentionally precipitate my death."*

56. Written guidance on issues connected with the withdrawal of consent is contained in the document Seeking Consent: Working with People in Prison which was published by the DoH in July 2002. The issues raised by the man's Living Will of February 2003 are so ethically complex and important that I make no apology for quoting extensively from the DoH Guidance.

57. The very first paragraph of the DoH document states:

"If your work involves providing health care to people in prison, you need to make sure you have your patient's consent to do what you are doing, if they are able to give it. Respect for people's rights to determine what happens to their own bodies is a fundamental part of good practice. It is also a legal requirement. The fact that a patient is also a prisoner does not affect their right to determine whether or not to accept treatment, where they have the mental capacity to make such a decision."

58. The second chapter of the document is headed Providing Care for Competent Adult Prisoners and states at paragraph 2.1:

"Before you provide treatment for a patient, you should ensure that you have their consent to do so. For a patient's consent to be valid, the person must:

- *have the capacity (be “competent”) to take that particular decision*
- *be acting voluntarily (not under duress)*
- *be provided with enough information to enable them to make the decision.*

Paragraph 2.2 adds:

“The law presumes that an adult has the capacity to take their own health care decisions unless the opposite is proved.”

Paragraph 2.5 of the document states:

“People with the capacity to take a particular decision are entitled to refuse any treatment being offered, even if this will clearly be detrimental to their health. No competent adult (defined as a person aged 18 or over) can be treated against their will.”

59. In Chapter 3 paragraphs 3.4 and 3.5 appear under the heading “Advance Statements” and read as follows:

“Sometimes people may have expressed clear views in the past as to how they would like to be treated if in future they were to lose capacity. Such views may have been expressed orally or in writing as “Advance Directives” or “Living Wills”.

“Advance Statements may take two forms: they may explicitly refuse particular treatment (when they are sometimes known as Advance Directives or Living Wills), or they may spell out the kind of care a person would wish to receive in certain circumstances.

“If a person makes an advance refusal of certain kinds of treatment, then such a refusal is legally binding if, at the time of making the decision, the individual was competent, they understood in broad terms the implications of their decision, and the refusal is applicable to their current situation. Advance statements setting out the kind of care the person would like to receive are not legally binding, but are influential when deciding what treatment is in the person’s best interest.”

60. Once the doctor was aware that the man was refusing his medication, he referred him to the Consultant Forensic Psychiatrist immediately. As early as 24 February 2003, the psychiatrist wrote to the doctor that the man’s “decision to discontinue his immuno-suppressants appears to be taken in clear consciousness and for reasons the logic of which can be followed.”
61. A much more detailed expert opinion was given by the psychiatrist in his letter to the doctor of 7 March 2003. The psychiatrist’s listed impressions were as follows:

- i. *"There is no mental illness;*
 - ii. *There is no obvious serious disorder of personality;*
 - iii. *He is not mentally impaired;*
 - iv. *There is no current risk of active deliberate self-harm (excluding the refusal of immuno suppressants);*
 - v. *I take the view that his refusal of immuno-suppressants is taken in clear consciousness, with knowledge of the consequences, and that it is not without such logic in his own eyes at least. It would appear that the man has the capacity to make such a decision about his care and treatment.*
 - vi. *Although I did not examine his mental state at the time of signing his Living Will, given my interviews with him which encompass that period, it would be difficult to suggest other than that he was in total possession of his faculties when he did so, i.e he knew what he was doing."*
62. The doctor and the man saw and corresponded with each other on a regular basis during the 21 months that the man spent at Durham. An important discussion about the Living Will took place on 28 June 2004. On 29 June the doctor wrote to him making eight points about the discussion of the previous day. His first points were:
- i. *"We are agreed that despite the slightly ambiguous wording of your Advance Directive, you do not wish at any time to be treated by dialysis;*
 - ii. *In the event of a cardiac arrest, you do not wish to be resuscitated.*
 - iii. *You will consider the redrafting of your Living Will/Advance Directive and I will send down my annotated copy of it for your consideration."*
63. Later the same afternoon, the doctor again wrote to him marking with two asterisks the area of his Living Will about which the doctor had a little concern. The doctor suggested some extra wording that he thought would indicate the man's intentions better, and he wrote that he hoped he did not sound too pedantic. The doctor ended his note to him with the following paragraph:
"Think about this and let me know your views. I am not in any way trying to pressurize you into having this redrafted but simply seeking to ensure that there is no confusion over your intentions."
64. In discussion with my investigator, the doctor explained that staff at the prison knew the man and his intentions very well indeed. The doctor was concerned that the man's intentions might not be followed by medical staff outside the prison, because they did not properly understand his wishes.

THE RELATIONSHIP BETWEEN THE HEAD OF PRIMARY CARE SERVICES AND THE MAN

65. It is very rare for a serving prisoner to make a Living Will. The doctor is immensely experienced – he told my investigator that his prison medical career stretches back 35 years – but this was the first time in his career that he had encountered such a situation. The Clinical Reviewer indicates that the man was seen on the day following his arrival at Durham by the doctor who, thereafter, coordinated his care. The existence of the Living Will and the man's absolute determination to discontinue his immuno-suppressant medication created notable ethical, professional and human rights challenges and dilemmas for the doctor and his colleagues at the prison. It is abundantly clear from examination of the clinical record that the doctor devoted a substantial amount of time to the man, and he did everything in his power to ensure that the prisoner's wishes were understood, respected and carried out.
66. The professional relationship between the two began on the morning of 18 February 2003, the day after the man's arrival at the prison on remand. Later that day, the doctor sent him copies of letters he proposed to send to doctors at a hospital in Newcastle who had cared for him, and he asked him to give his written consent for this course of action.
67. The doctor was vigorous in his efforts to secure the best possible clinical care for the man. For example, a letter of 23 April 2003 to the Consultant Renal Physician at a nearby hospital thanks her for spending a considerable time discussing the man with him and asks her to see the prisoner either at University Hospital of North Durham or in Durham Prison.
68. Evidence of a cordial relationship between the man and the doctor is contained in a letter from the man of 1 August 2003 to the doctor. He asks for the doctor's advice relating to his discharge from the HCC and ends the letter by saying:

"I also take this opportunity to thank you for the professional care and help you and your staff have shown me."
69. On 12 September 2003, he again wrote to the doctor complaining about his location on E Wing because his cell had no heating and he was finding his bone problem and pain worsening. The doctor wrote on 23 September 2003, indicating he would take such steps as he could to improve his location, and indeed five days later he was transferred to A Wing where he then remained for over nine months. The doctor also responded positively to his request that his blood chemistry tests should preferably not be done on Fridays or Mondays (those were his times for attending remedial gym).
70. A further amicable exchange of letters took place on 21 October 2003 when the doctor wrote that the man's bloods had come back virtually unchanged. The man wrote back:

“Thank you for this letter. I accept and agree with your suggestions, both to have my bloods checked and to consult with the Consultant Renal Physician. Thank her for coming in to see me here.”

71. A stream of correspondence then flows from the doctor's pen, both to his colleagues at Durham giving instruction on the man's clinical care and to expert colleagues in the community asking for their advice on anything more that he can do for his patient.
72. An exchange of correspondence took place in May 2004 between the doctor and the Principal Officer (PO) on the man's wing. The doctor explained that the man was currently not very well and had a condition which led him to feel cold much of the time. He said the provision of a kettle would be most helpful.
73. Two days later, the PO wrote back to the doctor stating that he had personally ensured that the man was issued with an electric cell kettle and assuring the doctor that he would be happy to provide any further assistance necessary. (The discussion in June 2004 about the man's Living Will and possible amendments to it has been scrutinised in the previous section.)
74. The man thanked the doctor in a letter of 17 August 2004 for the help he had been given so far. On 18 October 2004, he wrote to inform the doctor that his difficulty in breathing was much worse. He indicated that the effort it had taken to walk to a visit had been so great that he was now requesting to be moved to and from any future visits in a wheelchair.
75. To the layman, an especially impressive feature of the doctor's care for the man is that he left absolutely nothing to chance. On 20 October 2004, he wrote a series of letters to nursing staff, all Healthcare staff and doctors at HMP Durham, and to doctor colleagues at a hospital near the prison. In these letters, the doctor gave clear instructions to his colleagues about the actions they should take and not take in certain situations. He explained to nursing staff, for instance, that should the man suffer a cardiac arrest in their presence they should not take any action, although he recognised they would find it extremely difficult to restrain the instincts that they had applied down the years. The doctor disclosed to his colleagues that he would be away in Holland for a few days, but they were instructed to contact him directly should the situation become problematic and he supplied his mobile telephone number to staff in both the prison and the nearby hospital.
76. The doctor kept Durham's then governing Governor fully briefed on the complexities and options available in responding to the man's Living Will. A lengthy memo of 1 July 2004 advised the Governor that he needed to consider how, and in what detail, staff were to be informed of the man's wish not to be resuscitated were he to suffer a sudden cardiac arrest relating to the chemical imbalance in his blood.
77. In his last note to all staff dated 17 November 2004, the doctor wrote:

"It appears that the man is probably reaching the end of his life. Overall, I think everything is in place to manage his difficulties well and perhaps the most important aspect of his care relates to his analgesia."

In the second and last paragraph of the note the doctor adds:

"Clearly, we need to consider whether the man would be looked after in a NHS outside hospital, but at the moment I am not convinced that there is any more that would be done in hospital than we are achieving in the prison."

The Clinical Reviewer's conclusion in the next section of this report endorses the doctor's judgement on this question.

78. In her discussion with my investigator, the man's sister said that she spoke with the doctor very near the end of her brother's life about the option of outside hospital. The doctor told her that outside hospital would be cruel and she totally agreed with him.

CONCLUSIONS

79. In the conclusions and recommendations section of the Clinical Reviewer's report he writes that the doctor, together with consultant colleagues and nursing staff, went to great lengths to ensure that the man was fully briefed about the implications of his Living Will. The reviewer adds that there is no doubt that the man was competent to make the decision to refuse immuno-suppressive medication and to exercise his human right to do so. The reviewer observes that any attempts to provide medication against the man's will would have constituted an assault. He notes that the doctor considered alternative situations for providing care during the man's terminal phase. The advantage to the man would have been a pleasanter environment. The disadvantage, according to the reviewer, would have been that the patient would be removed from nursing and medical staff in whom he clearly had considerable confidence. The reviewer believes on balance that the decision not to move him in the latter stages of his illness was reasonable and justifiable. He ends his review by commenting that the doctor and his team are to be complimented on their efforts to care for the man whose management was complex and provided many ethical dilemmas for the clinical team. In particular, the doctor went to great lengths to ensure that he was always available to advise even when off duty or out of the country.

80. My conclusions echo those of the Clinical Reviewer. HMP Durham emerges with a great deal of credit from the way in which the complex ethical and human rights issues raised by the man's Living Will of 28 February 2003 were handled. I am completely satisfied that the three major questions raised by the DoH document *Seeking Consent* can be answered in the affirmative. These are:

- did the man have the capacity to take the particular decision that he wished to discontinue his immuno-suppressant medication?
- was he acting voluntarily without being under duress from anyone?
- was he provided with enough information to enable him to make the decision?

My conclusion is based on careful scrutiny of all available documentation, but particularly the Consultant Forensic Psychiatrist's expert opinion of 7 March 2003. The man was in total possession of his faculties when he signed the Living Will and he knew what he was doing.

81. The man's sister told my investigator that her brother was treated in a very humane and dignified fashion by the doctors and staff at Durham. He did not find it easy to trust the medical profession after his experiences in hospital in Newcastle. His sister indicated that he developed a grudging respect for the doctor because he treated him as another human being. The tone of the correspondence between the two men is amicable and respectful. It is abundantly clear that the doctor respected the man's right to determine what happened to his own body and he vigorously upheld that human right.

82. The doctor has modestly said to my investigator that he was part of a very large team effort at Durham to care for the man. I have no doubt that this was the case, and the sensitivity and humanity with which he was treated reflect a very strong commitment to the decency agenda by the Governor and his colleagues. There are many examples of this active commitment to decency throughout his time at Durham – the last week of his life being particularly notable. Arrangements were made for his sister and partner to stay through the night with him in the HCC between 16 and 17 November, and transport was supplied to take them to and from the prison. The continuous clinical record shows that an arrangement was made at 7:25pm on 16 November for the man's door to remain open at night with an officer sitting on the landing at a discreet distance. On 17 November, the doctor wrote to all staff with further advice about the man's care and how his pain was to be best controlled. It is very moving and inspiring to read the detailed entries made by the Nurse in the clinical record which explained the strenuous efforts she made to comfort, reassure and care for him during the last nights of his life.
83. The Prison Service's Business Plan for this year announces that the main priority is to ensure safe and decent conditions for prisoners and adds:
- "The ongoing drive to ensure decency in everything that we seek to accomplish with prisoners will remain."*
84. The Director General of the Prison Service is quoted in the Business Plan as saying:
- "And the overall test still remains: would I be content for my son or daughter to be locked up and treated in the way that prisoners are treated in this prison?"*
85. I conclude that the care afforded to the man demonstrated a commitment to decency to a degree I have rarely seen in over a quarter of a century visiting and writing about prisons.

NATIONAL RECOMMENDATIONS

1. I recommend that this report be drawn formally to the attention of the Director General of the Prison Service as an excellent example of decency in action.
2. The healthcare team led by the doctor should be commended for the compassionate way in which the man was supported, managed and cared for whilst at HMP Durham.
3. I concur with the doctor's opinion that it is extremely valuable for a Living Will or Advance Directive to be legally witnessed if at all possible. The ethical and practical issues raised by this case are very important. The Prison Service should give rapid attention to the best method of disseminating the learning that has been achieved at Durham.