Case 200401461: Lothian NHS Board

A complaints investigator with the delegated authority of the Scottish Public Services Ombudsman has conducted this investigation.

Summary

1. On 4 November 2004 the Ombudsman received a complaint from a man (referred to in this report as Mr C) that failures in the treatment and care that his 76 year-old mother (Mrs C) received in the Edinburgh Royal Infirmary (ERI) in November and December 2002 led to her death. My investigation did not uphold Mr C's central complaint but found that there were shortcomings in communication with Mrs C's family and significant deficiencies in her clinical records. In the light of these findings, the Ombudsman recommends that the University Hospitals Division of Lothian NHS Board (the Board) review the effectiveness of their medical records and the training of staff in their use.

Background

2. Mrs C was admitted to the ERI on 27 November 2002 with heart failure. Mrs C had been suffering from hypertrophic obstructive cardiomyopathy (HOCM) for a number of years. Mrs C was treated for the symptoms she was experiencing and initially progressed quite well. On 6 December Mrs C showed signs of worsening heart failure and doctors decided to make a change to her drug therapy. She suffered a cardiovascular accident (CVA) – a stroke - on 9 December and she died on 10 December 2002.

Complaint as put to the Ombudsman

3. Mr C complained of:

(a) inappropriate and unwanted changes in Mrs C's drug therapy;

(b) failure to keep Mrs C's family informed of her condition and in particular of her sudden change of condition on 9 December 2002;

(c) failure to respect the wishes of Mrs C's family about her treatment;

(d) failure to provide sufficient nursing care to Mrs C;

(e) failure to provide an adequate response to Mr C's complaint (by not continuing local resolution on medical issues);

(f) failure by the independent review convener to consider Mr C's complaint or Mrs C's medical records properly;

Investigation and findings of fact

4. The investigation of this complaint involved obtaining and reading all the relevant documentation, medical records and complaint files. I met Mr C and obtained advice from both the medical and the nursing advisers to the Ombudsman and a consultant cardiologist was consulted with particular reference to Mrs C's drug therapy. I made several written enquiries of the Board. I have set out, for each of the six heads of Mr C's complaint, my findings of fact and conclusions. The investigation has identified concerns about the standard of hospital records and I deal with these in paragraphs 51-60. Where appropriate, recommendations are set out at the end of the sections dealing with individual heads of complaint. A summary of recommendations is in paragraph 61. I have not included in this report every detail investigated but I am satisfied that no matter of significance has been overlooked. Mr C and the Board have been given an opportunity to comment on a draft of this report.

(a) Inappropriate and unwanted changes in Mrs C's drug therapy

5. Mr C first brought this matter to the attention of the staff nurse of Ward 31, in a letter dated 8 December 2002, in which he sought a meeting with the consultant cardiologist responsible for Mrs C's treatment (the consultant) to discuss recent changes to her drug therapy. Mrs C suffered a CVA early on 9 December and consequently Mr C never received a specific reply to this request. He did, however, discuss the changes at length with the specialist registrar on 9 December 2002, as a result of which, the decision to reintroduce Digoxin and discontinue

Securon (Verapamil) was reviewed and cancelled. This reversion to the original drug regime never actually took place as Mrs C died the next day. A meeting was arranged to discuss these matters with the consultant on 27 December 2002, after Mrs C's death.

6. Mr C had several remaining concerns, in relation to his mother's medication, and the medical adviser provided detailed advice on each of these. In the interest of clarity I will deal with each concern in turn.

7. *Securon (Verapamil).* This drug is used in cases of HOCM to reduce the workload of the heart by reducing the stiffness of the left ventricle. It is part of the natural progression of this condition that heart failure can develop as it did for Mrs C. Mr C complained that the dose of Verapamil was doubled from 120mg to 240 mg. Mrs C felt this drug had previously caused her to be very tired and lethargic and Mr C considered that it was at the root of the breathlessness and fluid build-up that had required her to be hospitalised on this occasion. Mr C said that he discussed these problems with the doctor in charge of his mother's admission and accordingly he had expected the drug to be withdrawn or reduced, not increased.

8. The hospital records indicate Mrs C was taking Verapamil on admission and continued to do so, but the discharge summary indicated that Verapamil was introduced during her stay rather than continued.

9. During local resolution, the consultant told Mr C that Verapamil could not have caused Mrs C's stroke and that her sudden deterioration was unforeseen.

10. The medical adviser commented that Verapamil is one of the standard drugs used to treat Mrs C's main condition, HOCM. He was satisfied that the decision to give Verapamil as prescribed was reasonable. The consultant also commented that Verapamil is an appropriate drug for patients with HOCM.

11. *Digoxin.* This is a drug that helps to regulate the heartbeat. Mrs C had previously been told that she would require to be on this drug for life and was very reluctant to change to an alternative drug. Mr C complained that he was only told

the Digoxin had been withdrawn, nearly a week after the event (it was withdrawn on 2 December 2002) and after he had been specifically told by a nurse there had been no change.

12. After the meeting on 27 December 2002, the consultant wrote to Mr C that Digoxin was prescribed for an irregular heart beat, which was not a feature of Mrs C's last illness, and that in any event it was not necessarily the drug most cardiologists would choose for this purpose.

13. The medical adviser commented that, although Mr C believed that the withdrawal of Digoxin caused Mrs C's condition to worsen, this would not have been the case. The adviser suggested that the drug was stopped because it might have been causing harm. He concluded that the withdrawal of the drug was a reasonable decision since it is not effective in preventing arterial fibrillation (ineffective pumping of the blood around the heart). The consultant confirms this view.

14. *Beta-blocker.* These are drugs that reduces blood pressure and the workload of the heart. Following Mrs C's stroke on 9 December, she was given Atenolol, a beta-blocker. Mr C complained that his mother had had a very adverse reaction to this drug a number of years ago. He believed the drug had previously been withdrawn because it had caused Mrs C to suffer a haemorrhage. When she was admitted to the ERI in November 2002 he objected to her being given this drug and he found it necessary to threaten legal action to prevent it being given to her.

15. The medical adviser commented that there is no record of this previous haemorrhage and that Atenolol would not cause haemorrhage.

16. *General.* The medical adviser said that he considered the drug treatment given during Mrs C's last admission was appropriate. The adviser also said that he understood Mr C's concern that certain symptoms seemed to follow changes in drug therapy. It is often difficult to determine whether symptoms are due to the underlying condition or to the side effects of drug therapy. In this case it was probable that some of the fatigue could have been a drug side effect, but it is also

a symptom of heart disease. The medical adviser could not find any evidence that the administration of drugs, or their withdrawal, had had any significant adverse effect. He considered that a full explanation was given during Mrs C's admission and in response to the complaints.

17. In commenting on the draft of this report Mr C said that he still considered the decision to change his mother's drug regime was wrong. In particular, he considered the decision to reintroduce Digoxin and discontinue Verapamil, after he had disputed the earlier change with the specialist registrar on 9 December, illustrated that the doctors were experimenting with his mother's drug regime and that they had realised they were wrong.

18. In commenting on the draft report the Board said that there was no documentary evidence that Mrs C objected to her change of drug therapy. I would note that the sparse nature of the medical records does not give me sufficient confidence in their accuracy to consider them conclusive. The Board have acknowledged the importance of listening to and documenting relative's concerns about treatment, even when these concerns may be based on misconception. They have also noted that this does not mean that treatment has to be altered according to the family's wishes, as the physician's responsibility is to provide appropriate treatment.

Inappropriate and unwanted changes in Mrs C's drug therapy: conclusions

19. Mrs C received different drugs for a variety of reasons. Mr C's view of the effect of these drugs and the reasons for their use did not always accord with that of the doctors treating Mrs C during her last admission. However, based on the advice I have received I am satisfied that the drugs were appropriately and properly administered and that sufficient explanations were given to her family at the time. I agree with the Board's view of the physician's responsibility expressed in paragraph 18. I note, however, that, in this case, the specialist registrar did agree to change the drug regime on 9 December 2002, although the Board have since maintained that the removal of Digoxin and introduction of Verapamil was the appropriate course of action. Nonetheless, based on the clinical advice I have received, I am of the view that the change in Mrs C's drug regime was clinically

appropriate and I do not uphold this head of complaint. The Ombudsman has no recommendation to make in this respect.

(b) Failure to keep Mrs C's family informed of her condition and in particular of her sudden change of condition on 9 December 2002

20. Mr C complained that the family was told on 1 December 2002 that his mother's condition was improving and the plan was for her to return home shortly. In fact her condition worsened and her family was not informed that the plan for her return home had changed or that her condition was worsening. Mr C said that he asked about his mother's condition every day and was not informed of any changes or deterioration. He complained that this gave the impression his mother was doing well but subsequently (during the local resolution stage of the NHS complaints process) he was told that she was in fact very ill.

21. When the consultant wrote to Mr C on 13 February 2003 (see paragraph 42) he expressed regret that he was on holiday during the final week of Mrs C's life and that Mr C was not made fully aware of the true extent of Mrs C's illness and the seriousness of her condition.

22. During the local resolution stage of the NHS complaints process the Board stated that the comment from nursing staff, with respect to Mrs C's expected discharge, was made following a request for a physiotherapy assessment which had been taken as a sign she was soon to be ready for discharge. The consultant stated that in fact she had never been well enough for discharge to be considered.

23. Mr C further complained that it was only when he contacted the hospital on the morning of 9 December 2002, to arrange a meeting with a member of medical staff, that he was asked to come in. He was not, however, made aware that his mother's condition had deteriorated and he was not prepared for seeing her so unwell on his arrival in hospital later that morning.

24. During local resolution the Board commented on the fact that the records show staff contacted a member of the family on the day of Mrs C's death. I note that the record does not state which member of the family was contacted. Mr C's complaint

in fact related to the failure to notify him after his mother's stroke on the previous day, a point never answered.

25. The hospital record for 9 December 2002 (no time recorded) indicated the plan was for the specialist registrar to discuss the suspected stroke with Mr C, although it was not detailed how or when this was expected to happen. There is no record of Mr C being contacted. Mr C said that staff informed him that his mother had suffered a stroke somewhere between 03:00 and 06:00. There is a timed record, at 10:30, detailing a long discussion between Mr C and the specialist registrar.

26. The nursing adviser commented that, while there was a comprehensive nursing care plan for Ward 31, she was concerned that many of the details with respect to Mrs C's care were not completed. In particular she noted that there were no entries in relation to discharge planning, and that the lack of clear documentation meant that she could not comment on the information given to Mrs C and her family in relation to this by the nursing staff. However, it was clear that the family did not feel they had received adequate information. The nursing adviser also drew attention to the lack of evidence of reassessment and care planning following the considerable change in Mrs C's condition and nursing needs on 9 December. She commented that from this date Mrs C was highly dependent and the documentation in the care plan did not adequately reflect this.

27. In response to enquiries the Board said that it was recognised that there had been a lack of communication between clinical staff and relatives in this case. A number of changes were made to compulsory staff training to address this issue.

Failure to keep Mrs C's family informed of her condition and in particular of her sudden change of condition on 9 December 2002: conclusions

28. The lack of adequate documentation in itself gives rise to concerns that I will deal with in paragraphs 51-60 below. As the nursing adviser commented, the lack of clear documentation means that I cannot comment on the information given to Mrs C and her family, but it is clear that the family did not consider it to be adequate. In the absence of written records to the contrary, I uphold the complaints that Mrs C's family were not made aware of the seriousness of her

condition and that Mr C was not contacted when his mother's condition changed on 9 December 2002.

29. I note that the Board have already apologised and made changes in staff training in recognition of this failing. Given this, the Ombudsman has no recommendation to make. However, she requests the Board to provide her with evidence of how this revised policy and the additional training provided to staff in relation to communication have made a difference to the experience of patients.

(c) Failure to respect the wishes of Mrs C's family about her treatment

30. Mr C complained that Mrs C's drug treatment was changed despite the objections of his mother and the family. He further complained that his mother was not put on life-support systems when her heart stopped although he and his brother had discussed this with the doctor.

31. *Drug Treatment***.** During local resolution the consultant acknowledged that Mr C had discussed his mother's drug therapy with the doctor on admission but that this was not recorded. He said that drug prescriptions would be discussed in the first instance with the patient rather than the family but that staff would not force a patient to take medication. It was also noted by both the advisers that there were no entries in the record regarding Mrs C's reluctance to take certain medications. This is despite the fact that Mr C raised this as an issue with staff at the time and that a member of staff told Mr C that he had spent two and a half hours trying to persuade her to take her new prescription. I also note the views and concerns expressed by Mr C about the implications of the decision to revert to the original drug regime, following a conversation between the specialist registrar and Mr C on 9 December 2002 (see paragraph 17).

32. The nursing adviser commented that the preadmission care assessment documents Mrs C's questionable understanding about her medication and condition but contained no plan as to how this would be managed.

33. *Life Support.* The hospital record for 10 December 2002 noted a conversation with Mrs C's husband and sons regarding resuscitation but commented that they

were not keen to discuss the matter, although the doctor indicated he did not feel resuscitation would be appropriate.

34. The medical adviser said that he considered that this view on the part of the doctor was reasonable, taking into consideration all aspects of Mrs C's condition. He also pointed out that the General Medical Council (GMC) issued detailed guidance to doctors on obtaining patients' consent to treatment and on withholding and withdrawing life-saving treatment. The guidance deals, among other things, with establishing whether patients have the capacity to make informed decisions; taking account of the views of patients' relatives; and recording decisions. Relevant extracts from the GMC guidance are set out at Appendix 3 to this report.

35. Having read the draft report, the Board commented that the medical record indicated that the issue of withholding resuscitation was discussed with the family and that there was no record of the family expressing a conflicting view. They further commented that it might not always be appropriate to press close family members to discuss resuscitation issues if they do not wish to do so.

Failure to respect the wishes of Mrs C's family about her treatment: conclusions

36. Clearly, Mr C did not agree with the drug therapy being provided to his mother and he believed she did not support it either. He also stated that he disagreed with the decision to not provide life-support/resuscitation to his mother after her stroke. The medical record does contain evidence that both these issues were discussed with Mr C by doctors, although there is very little detail regarding the decision not to resuscitate and confusion regarding the changes in drug regime. The GMC guidance (Appendix 3) says that doctors 'must ensure that decisions are properly documented, including the relevant clinical findings; details of discussions with the patient, health care team, or others involved in decision making'. That did not happen in this case. On the documentary evidence available to me I am not persuaded that sufficient attention was given to the views Mrs C's family expressed about her treatment. I am not suggesting that the decisions not to resuscitate or to change the drug regime were clinically incorrect. However, I have already mentioned in paragraph 27 that the Board have recognised failures in communication and undertaken an extensive review of this. With this in mind the

Ombudsman has no further recommendation to make.

(d) Failure to provide sufficient nursing care to Mrs C

37. Mr C complained that his mother was frequently left uncovered and became cold and that on the evening before her stroke she was left to wander around the ward, tiring herself out and contributing towards her stroke.

38. During the local resolution stage of the NHS complaints process the Board apologised to Mr C if he felt insufficient efforts had been made to keep Mrs C covered but pointed out that she was very restless in bed.

39. At the local resolution meeting on 9 March 2004, the Board explained to Mr C that his mother's stroke was not predictable and that there was, therefore, no reason to restrict her movements.

40. The nursing adviser commented that her review of the nursing notes and plan and specifically the absence of some nursing documentation made it impossible for her to comment on all aspects of Mr C's complaint. She noted that there were only five nursing entries for the period from 27 November to 10 December 2002. However, the nursing adviser commented that it would not have been appropriate to have used bed rest as a nursing management strategy for Mrs C's care prior to her condition change on 9 December 2002 because of potential disadvantages associated with immobility.

Failure to provide sufficient nursing care to Mrs C: conclusions

41. The Board have already provided an apology for any failure to cover Mrs C and based on the advice I have received, I believe it was appropriate to allow Mrs C to move freely around the ward. I do not uphold this aspect of Mr C's complaint.

(e) Failure to provide an adequate response to Mr C's complaint (by not continuing local resolution on medical issues)

42. Mr C met the consultant on 27 December 2002 and received a follow-up letter dated 13 February 2003. He then approached the Board with a formal complaint in September and October 2003. He received a formal response in November 2003.

Mr C remained dissatisfied and wrote again in December 2003 and was advised in January 2004 of his right to ask for an independent review. It was agreed at this point to try for further local resolution and a meeting was arranged for 9 March 2004, following which Mr C received a further letter dated 17 March 2004. Mr C was not satisfied after this meeting and requested a further meeting. This was declined by the Board who advised him again of his right to seek an independent review.

43. Mr C complained that the Board 'closed the door' on local resolution when he believed it would still be helpful to have a further meeting.

Failure to provide an adequate response to Mr C's complaint (by not continuing local resolution on medical issues): conclusions

44. In this case local resolution included a number of written responses and a meeting with appropriate staff members. I believe it was reasonable of the Board to consider by March 2004 that local resolution had ended and advise Mr C to ask for an independent review if he remained dissatisfied. I do not uphold this aspect of the complaint.

(f) Failure by the independent review convener to consider Mr C's complaint or Mrs C's medical records properly

45. Mr C requested an independent review on 4 July 2004. Under the NHS complaints procedure then in force, a convener considered such requests. This would usually be a non-executive director of the NHS body concerned. In reaching a decision, the convener was required to consult a prospective lay panel chair and, where clinical issues were involved, seek appropriate professional clinical advice. The guidance on the NHS complaints procedure set a target time of 20 days for response to requests for independent review.

46. On 19 July 2004 the convener wrote to Mr C asking him to confirm the points he wished to raise and give consent to access his mother's medical records. Mr C said he did not receive this letter until 26 July 2004. Before Mr C had had an opportunity to respond, the convener met the chair and clinical adviser on 2 August 2004. They discussed Mr C's complaint and wrote to him on this date advising him

that there would not be an independent review of his complaint, as all points had been answered.

47. Mr C complained that, as they had not yet had confirmation of the outstanding points or his permission to access his mother's records, they could not have given due consideration to the matter.

48. In response to enquiries the Board said that guidance on the NHS complaints procedure in place at that time required the convener to make a decision within 20 days of a request. In this case the meeting was held 19 days after receipt of the request. The Board also said that the clinical adviser, who would have had the medical authority to do so, reviewed Mrs C's medical records and that the convener or chair did not review them.

49. It is important to note that there has recently been a major change to the NHS complaints procedure. Since 1 April 2005 the independent review stage of the NHS complaints procedure has been removed, with complainants being able to approach the Ombudsman immediately on completion of local resolution.

Failure by the independent review convener to consider Mr C's complaint or Mrs C's medical records properly: conclusions

50. I do not consider that it was reasonable to have expected Mr C to respond so promptly to the request he received on 26 July 2004, particularly when he was not given any indication that there was such a tight time frame. The 20-day timescale was a target and as such adherence to it was not compulsory and could be varied if circumstances made this necessary. To that extent, I uphold this aspect of Mr C's complaint to the Ombudsman. However, in light of the changes to the NHS complaints procedure there would be no purpose served in making any specific recommendation in this regard.

Standard of hospital records

51. Hospital documentation for the ERI uses a combination of unitary patient record (UPR), which allows for multidisciplinary input to the record, and pre-printed care plans, which cover specific aspects of care, for example dietary needs.

52. As this investigation progressed, it became apparent that a number of the issues raised by Mr C revealed an underlying problem with the quality of hospital documentation in this case. I have noted above several instances where the hospital record did not detail conversations with Mrs C or her family, nor actions taken by staff.

53. The nursing adviser also expressed considerable concern that the hospital records, as a whole, were particularly sparse. She said that, in her view, the nursing records were of a poor standard and did not provide sufficient documentation on the nursing care received by Mrs C.

54. In response to enquiries, the Board made a number of comments regarding the absence of records:

> 'The nursing care plan for Ward 31 appears not to have been applied in an entirely consistent manner, but overall this did not lead to any confusion with the patient's nursing management.'
>
> 'Unfortunately there is no evidence that the care plan was updated on 9 December 2002, following the change in her condition. However, there is evidence of this in the UPR. It could be interpreted that, due to the high level of care that the patient was receiving that day, due to the gravity of her condition, updating the care plan may not have been a priority.'
>
> 'It is unfortunate that not all communications with the family were noted. However, this should not be interpreted as meaning that such communications were non-existent.'

55. The nursing adviser reviewed the comments of the Board. She remained concerned that, while the Board recognised the fact that there were omissions, such as the failure to update the care plan on 9 December 2002, their response suggested that these areas of poor practice were reasonable, given the context of care. She did not support this view, as there is a clear minimum standard for

recording nursing interventions and changes in the nursing plan. The current Nursing and Midwifery Council guidelines for record-keeping state:

> 'Record-keeping is an integral part of nursing … practice. It is a tool of professional practice and one that should help the care process. It is not separate from this and it is not an optional extra to be fitted in if circumstances allow.'
>
> *(Nursing and Midwifery Council Guidelines for Records and Record Keeping January 2005)*.

56. The nursing adviser commented that it might be that the quality of oral communication between nurses and other inter-professional communication was of a reasonable standard (that is, that the nursing staff provided the medical staff with updates about the changes to the patient's condition). Without documentary evidence for this, the nursing adviser argued that the care provided fell below the reasonable standards required for professional nursing. She said that it is of particular concern that the Board continues to fail to acknowledge the potential for this failing to occur.

57. The nursing adviser commented that the use of the UPR to avoid unnecessary duplication of recording was a sensible one. However, she considered that the use of pre-printed care plans minimised the scope for individualised patient care. She identified a number of omissions in the care plans for Mrs C.

Standard of hospital records: conclusions

58. I acknowledge the view of the Board that lack of records may not necessarily indicate a failure. However, it is precisely this lack of clarity or certainty, which has given rise to a number of concerns in this complaint and prevents me from reaching clear conclusions on others. It is also clear that, based on the advice I have received, there has been a failure to ensure record-keeping meets GMC and NMC guidelines. That is a matter of concern.

59. In the light of these findings I am of the view that the Board should review the scope of the UPR and responsibilities for documenting in that record; provide further training for staff with regard to care plans; establish an ongoing framework for evaluating nursing care; and consider the comments about record-keeping detailed in this report.

I am aware that these are major pieces of work. I am also aware that an independent panel has been set up to advise NHS Lothian on the care of older patients. This aims to bring an objective view on best practice in looking after patients' personal and emotional needs, as well as providing high-quality medical treatment. I will ensure that the independent panel receives a copy of this report.

Summary of recommendations

60. Following the investigation of all aspects of this complaint the Ombudsman recommends that the Board:

i. reviews the scope of the UPR and nursing responsibilities for documenting in this record;

ii. provide further training for staff in relation to maximising the benefits of care plans, (in particular, this should address the specific issues for each patient);

iii. establishes an ongoing framework for evaluating nursing care to include auditing of documentation and of the overall patient experience;

iv. consider the comments about record-keeping alongside any recommendations made by the independent panel on the care of older patients.

Further action

61. As noted in paragraph 4, the Board were given an opportunity to comment on the draft of this report. They said that they accept the recommendations and will

act on them accordingly. The Ombudsman asks the Board to notify her when and how the recommendations are implemented.

20 December 2005

Appendix 1

Explanation of abbreviations used

Mr C	The complainant
Mrs C	Mr C's mother who died
ERI	Edinburgh Royal Infirmary
GMC	General Medical Council
The Board	Lothian NHS Board
The consultant	Consultant cardiologist responsible for Mrs C's treatment
UPR	Unitary patient record

Appendix 2

Glossary of medical terms

Arterial fibrillation	Ineffective pumping of the blood around the heart
Beta-blocker	These are drugs that reduces blood pressure and the workload of the heart
CVA	Cardiovascular accident
Digoxin	This is a drug that helps to regulate the heartbeat
HOCM	Hypertophic obstructive cardiomyopathy
Securon (Verapamil)	This drug is used in cases of HOCM to reduce the workload of the heart by reducing the stiffness of the left ventricle

Appendix 3

EXTRACTS FROM GENERAL MEDICAL COUNCIL

GUIDANCE TO DOCTORS

SEEKING PATIENTS' CONSENT: THE ETHICAL CONSIDERATIONS

November 1998

Consent to investigation and treatment

Providing sufficient information

4. Patients have a right to information about their condition and the treatment options available to them. The amount of information you give each patient will vary, according to factors such as the nature of the condition, the complexity of the treatment, the risks associated with the treatment or procedure, and the patient's own wishes. For example, patients may need more information to make an informed decision about a procedure which carries a high risk of failure or adverse side effects; or about an investigation for a condition which, if present, could have serious implications for the patient's employment, social or personal life.

Establishing capacity to make decisions

19. You must work on the presumption that every adult has the capacity to decide whether to consent to, or refuse, proposed medical intervention, unless it is shown that they cannot understand information presented in a clear way. If a patient's choice appears irrational, or does not accord with your view of what is in the patient's best interests, that is not evidence in itself that the patient lacks competence. In such circumstances it may be appropriate to review with the patient whether all reasonable steps have been taken to identify and meet their information needs (see paragraphs 5-17). Where you need to assess a patient's capacity to make a decision, you should consult the guidance issued by professional bodies.

'Best interests' principle

25. In deciding what options may be reasonably considered as being in the best interests of a patient who lacks capacity to decide, you should take into account:

- options for treatment or investigation which are clinically indicated;
- any evidence of the patient's previously expressed preferences, including an advance statement;
- your own and the health care team's knowledge of the patient's background, such as cultural, religious, or employment considerations;
- views about the patient's preferences given by a third party who may have other knowledge of the patient, for example the patient's partner, family, carer, tutor-dative (Scotland), or a person with parental responsibility;
- which option least restricts the patient's future choices, where more than one option (including non-treatment) seems reasonable in the patient's best interest.

WITHHOLDING AND WITHDRAWING LIFE-PROLONGING TREATMENTS: GOOD PRACTICE IN DECISION MAKING

August 2002

Adult patients who can decide for themselves

13. Adult competent patients have the right to decide how much weight to attach to the benefits, burdens, risks, and the overall acceptability of any treatment. They have the right to refuse treatment even where refusal may result in harm to themselves or in their own death, and doctors are legally bound to respect their decision. Adult patients who have the capacity to make their own decision can express their wishes about future treatment in an advance statement.

15. Where adult patients lack capacity to decide for themselves, an assessment of the benefits, burdens and risks, and the acceptability of proposed treatment must be made on their behalf by the doctor, taking account of their wishes, where they are known. Where a patient's wishes are not known it is the doctor's responsibility

to decide what is in the patient's best interests. However, this cannot be done effectively without information about the patient, which those close to the patient will be best placed to know. Doctors practising in Scotland need additionally to take account of the Scottish legal framework for making decisions on behalf of adults with incapacity.

Choosing between options: difference of view about best interests

16. Applying these principles may result in different decisions in each case, since patients' assessments of the likely benefits and burdens or risks, and what weight or priority to give to these, will differ according to patients' different values, beliefs and priorities. Doctors must take account of patients' preferences when providing treatment. However, where a patient wishes to have a treatment that - in the doctor's considered view - is not clinically indicated, there is no ethical or legal obligation on the doctor to provide it. Where requested, patients' right to a second opinion should be respected.

17. Where a patient lacks capacity to decide, the doctor, health care team or those close to the patient involved in making the decision, may reach different conclusions about the patient's preferences and what course of action might be in the patient's best interests. In these cases it is important to take time to try to reach a consensus about treatment and it may be appropriate to seek a second opinion, or other independent or informal review.

18. In the rare circumstances where any significant disagreement about best interests cannot be resolved, legal advice should be sought on whether it is necessary to apply to the court for a ruling. Doctors practising in Scotland would need to take account of the statutory procedures for resolving disagreements.

Recording decisions

63. You must ensure that decisions are properly documented, including the relevant clinical findings; details of discussions with the patient, health care team, or others involved in decision making; details of treatment given with any agreed review dates; and outcomes of treatment or other significant factors which may affect future care. You should record the information at the time of, or soon after, the events described. The record should be legible, clear, accurate and

unambiguous, for example avoiding abbreviations or other terminology that may cause confusion to those providing care. You should ensure that the records are appropriately accessible to the patient, team members and others involved in providing care to the patient.