KATHARINE HOUSE HOSPICE

Policy and Procedures for Access to Health Records, including Copying Letters to Patients

Approved by:

Date of approval:

Originator: **Medical Director**

POLICY STATEMENT

All living patients or their authorised representatives have a legal right to see their health records under the Data Protection Act 1998.

All parties requiring legitimate access to the health records of deceased patients can do so under the Access to Health Records Act 1990.

The NHS Plan 2000 stated that patients should be able to receive copies of clinicians' letters about them as a right. The Department of Health subsequently issued guidelines about how to ensure that patients received such letters if they wished, and the safeguards that need to be followed.

The legal consequences of errors in these areas of practice are potentially very significant.

Related Hospice policies/procedures:

Confidentiality policy.
Information management policy.
Policies and procedures for the creation, completion, management, handling and storage of patient records.

POLICY

Aim and Scope of the Policy

The Policy summarises the legislation and the senior management decisions regarding the handling of these matters.

Staff Responsibilities

The Director of Nursing (as Registered Manager)	Responsible for ensuring that the policy and procedure is in place and adhered to. Responsible for ensuring that the content of the policy and procedure is in line with statutory requirements and professional guidance. Ensures that clinical staff and other staff, as appropriate, are aware of the policy and procedure and how to apply it. Ensures that patients are aware through the provision of suitable information materials.
All Clinical Staff	Responsible for compliance with the policy and procedure.

A consideration of the general approach to writing health records

Health Care professionals must keep clear, accurate, legible and contemporaneous patient records which report the relevant clinical findings, the decisions made, the information given to patients and any drugs or other treatment prescribed. Records must be legible and factual. In the rare instances where it might be appropriate to document non-clinical views about the behaviour, motives or temperament of the patient or their family and friends, this should be done with sensitivity and have a clear potential bearing on future care.

It is prudent for all healthcare records to be written and catalogued with definite regard to the possibility that the patient, a patient representative, or other legitimate person may subsequently request to see them. With this in mind, it may also be helpful for the senior clinical staff to routinely highlight any parts of any patient record that should not be disclosed for any of the legitimate reasons listed later in this policy if a subsequent request is made to view the records.

As all patients have a right to view their health records, all letters should be written in the knowledge that they may be read by the patient at some future point. Therefore they should not contain any thoughts or opinions that could surprise, shock or offend the patient should they happen to read them, even if it is not intended to send them a copy at the time they are actually written.

If, at any point, a patient expresses a view about future disclosure to third parties, this should be documented in the records. Doctors may wish to initiate discussion about future disclosure with some patients if it seems foreseeable that controversial or sensitive data may be the issue of a future dilemma, for example after the patient's death.

KATHARINE HOUSE HOSPICE

Access to health records by living patients or their representatives

All manual and computerised health records about living people, regardless of when they were made, are accessible to the following people under the Data Protection Act 1998:

- Competent patients of any age wishing to access their own records.
- Third parties authorised by a competent patient to act on behalf of the patient.
- Parents of children, if this is in the child's best interests and not contrary to the child's wishes if competent to express a wish.
- People appointed by a court to manage the affairs of mentally incapacitated adults, in order to access information necessary for them to fulfil their function.

Formal applications for access must be made in writing to the most appropriate Clinical Director, and accompanied by the appropriate fee if this is required. Access must be given within 40 days of receipt of a request and fee from an identifiable and authorised applicant.

There are eight explicit areas of information that must not be disclosed to patients or their representatives. These are summarised in Table One. There is no obligation to inform patients if information is withheld on any of these grounds. The only times these exemptions do not apply are when disclosure of such material is required by law or is necessary for the purposes of establishing, exercising or defending legal rights. Decisions about what and what not to disclose must be made by the appropriate Clinical Directors and, as all health records typically include both nursing and medical entries, this will inevitably be a joint decision-making process. If the applicant disputes the decision of the Clinical Directors to withhold information for any of the legitimate grounds, they can apply to the courts who have the power to order disclosure or non-disclosure as they see fit.

Whilst records must not be tampered with between the time of the request and their supply for inspection by the patient or their representative:

- Amendments or deletions between the request and the supply of the records can be made, but only if these same changes would have been made regardless of the request.
- The Clinical Directors can offer to delete any inappropriate comments, and may find it helpful to discuss any potentially distressing entries that do not fall within any of the eight exclusion categories with patients in advance of access.

Any amendments to records must be made in a way that indicates why the alteration was made so that it is clear that records have not been tampered with for any underhand reason. After all legally required exclusions have been made (and any inappropriate comments have been removed with the prior permission of the patient) it is necessary to disclose all other information in the health records in their entirety to the patient or their representative.

Table One: A summary of the material that must be excluded from view to the patient or their representative when they ask to see the health records

1) Third parties Information relating to identifiable third parties may not be released unless:
   a) the third party is a health professional who has compiled or contributed to the health records or who has been involved in the care of the patient;
   b) the third party gives consent to the disclosure; or
   c) it is reasonable to dispense with that third party's consent.
   Doctors must still disclose as much of the information in the records as is possible. The Act suggests that it may be necessary to omit names and identifying particulars from the records before disclosure, and care should be taken to ensure that the information is genuinely anonymous.
2) Harm Access must not be given to any information which, in the opinion of the appropriate health professional, would be likely to cause serious harm to the patient or another person. Circumstances in which information may be withheld on these grounds of harm are extremely rare. This exemption does not justify withholding comments in the records because patients may find them upsetting. The BMA advises that if harm could arise from providing access, advice from others involved in providing care may be helpful in assessing the nature and extent of the risk. This is one reason why both Clinical Directors jointly inspect the records before making them available to the applicant for inspection.
3) Confidentiality When a third party applies for access on behalf of a patient no information can be disclosed which the patient had provided on the understanding that it would be kept confidential or about which the patient had requested non-disclosure. It is helpful to clearly mark such details in the health records as they are entered or when the patient subsequently requests for confidentiality over the matter in question.
4) Legal privilege Access may not be given to records which are subject to legal professional privilege. This may arise in the case of an independent medical report written for the purpose of litigation.
5) Court proceedings The courts have the power to restrict access to information as to the physical or mental health or condition of the patient supplied to the court in a report or other evidence from a local authority, Health and Social Services Board, Health and Social Services Trust, probation officer or other person in the course of certain family and children court proceedings.
6) Fertility treatment No information may be disclosed about the keeping or use of gametes or embryos or whether any identifiable individual was, or may have been, born as a result of fertility treatment (in vitro fertilisation or the use of donated ova, sperm or embryos).
7) Children No information can be disclosed that is already prohibited in legislation concerning adoption records and reports, statements of a child's special educational needs and parental order records and report.
8) Other information The Secretary of State may make further orders to exclude other types of data if this is necessary to safeguard the interests of patients or the rights and freedoms of others.

Patients are entitled to a copy of their records, for example a photocopy of paper records or a printout of computerised records. The copy must be accompanied by an explanation of any terms that are unintelligible. A small fee can be charged when showing or providing copies of health records to patients or their representatives. There are strict rules regarding pricing, and up-to-date guidance can be found on the British Medical Association web site.

After inspecting their health records, a patient may request that any information they believe to be inaccurate is corrected. There is no obligation for health professionals to accept the patient's opinion, but the patient's request must be fully documented in the notes and it is recommended that a copy of the correction or appended note is given to the patient. If they remain dissatisfied, patients have the right to apply to court to have inaccurate records amended or any expression of opinion based on them removed.

Procedure for access to health records by living patients or their representatives

1. Any patient or patient representative requesting access to Katharine House Hospice health records must be issued with a copy of this procedure for reference purposes, and advised to make a formal request in writing to the Director of Nursing or the Medical Director. They can also be supplied with a complete copy of the "Policy for Patient Access to Health Records, including Copying Letters to Patients", if they so request.

2. The letter must include:
    - The date it was written.
    - Full name, address and date of birth of the patient.
    - Relationship of the applicant to the patient.
    - When the applicant is acting as a patient representative, written confirmation of this fact signed by the patient or some equally verifiable evidence.
    - Whether simple inspection of the notes is sufficient or whether a copy of the notes is also required.
    - Whether they want any inappropriate comments to be removed from the records before they inspect them (in the highly unlikely event of any having been made in the first place)
    - An agreement to pay any fee that might be requested, that will not exceed the sum indicated in the British Medical Association guidance.

3. We would also appreciate the applicant voluntarily advising us what is being sought from the notes, although there is absolutely no obligation for them to do so. This is for the simple reasons that:
    - Dialogue often clears up any knowledge gaps, misunderstandings or concerns more satisfactorily than examination of the records.

- It might be possible to provide a patient (but not a patient representative) with direct access to the information they want in the health record without the need for such a formal procedure.

4. The Clinical Director who receives the letter dates it upon receipt and sends back a written response by return of post. If the recipient is on leave then the letter is passed to the other Clinical Director for action. The letter of reply either:
   - Confirms that the process is underway.
   - Explains if anything further needs to be done before the process can start, or
   - Advises the applicant that their application has not been accepted, and on what grounds.

5. Any material that falls within the eight categories defined in the Data Protection Act 1998 that must not be disclosed to the applicant is removed from the record. It might be necessary to temporarily replace genuine pages from the health record with photocopied pages that have had the sensitive information deleted from it.

6. If the applicant has also agreed to the removal of inappropriate comments from the records, then these are removed too.

7. Once the records have been prepared for inspection, the applicant is advised by telephone and a mutually convenient appointment is made with one of the Clinical Directors for their inspection.

8. The presence of the Clinical Director allows for:
   - Interpretation of any poorly legible handwriting.
   - Explanation of any difficult clinical terminology.

9. Copies are made of anything in the notes requested by the patient. Any explanations required by the patient are also written down by the attending Clinical Director for the applicant to take away with them for subsequent reference.

10. The applicant has the right to take legal action if they feel that information is being wrongfully withheld.

KATHARINE HOUSE HOSPICE

Access to the health records of deceased patients

The personal representative, executor, administrator or anyone having a claim resulting from the death of a patient has a right to apply for access to any of the deceased patient's records made since 1 November 1991. There is no statutory right of access to records of deceased patients made before 1 November 1991, except those parts that may be required to make any later part of the record intelligible. The applicant can request to simply inspect the records or to receive a copy of them.

All such requests must be made in writing to one of the Clinical Directors who, once satisfied that the applicant is entitled to the information, will make the records available within 21 days if the record has been amended or added to in the previous 40 days, or within 40 days if no amendments or additions had been made in the previous 40 days.

When handling such requests, the same standards of confidentiality must extend to the dead as to the living. Only information that is directly relevant to the claim must be released. Information can further be denied if:

- it identifies a third party without that person's consent unless that person is a health professional who has cared for the patient;
- in the opinion of the relevant health professional, it is likely to cause serious harm to somebody's physical or mental health; or
- the patient gave it in the past on the understanding that it would be kept confidential. Similarly no results of examinations or investigations which the patient thought would be confidential at the time they were carried out can be disclosed. No information at all can be revealed if the patient requested non-disclosure.

The applicant has the right to take legal action if they feel that information is being wrongfully withheld.

Procedure for access to health records by legitimate parties after the death of a patient.

1. Any person requesting access to Katharine House Hospice health records for a deceased patient must be issued with a copy of this procedure for reference purposes, and advised to make a formal request in writing to the Director of Nursing or the Medical Director. They can also be supplied with a complete copy of the "Policy for Patient Access to Health Records, including Copying Letters to Patients", if they so request.

2. The letter must include:
    - The date it was written.
    - Full name, address and date of birth of the patient.
    - Relationship of the applicant to the patient.

- The specific purpose for their request as, in the interests of patient confidentiality, the applicant is only entitled to access information that directly addresses that purpose. (Failure to supply this information means that the request cannot be processed).
- Whether simple inspection of the clinical extracts is sufficient or whether a copy of the notes is also required.
- An agreement to pay any fee that might be requested, that will not exceed the sum indicated in the British Medical Association guidance.

3. The Clinical Director who receives the letter dates it upon receipt and sends back a written response by return of post. If the recipient is on leave then the letter is passed to the other Clinical Director for action. The letter of reply either:
    - Confirms that the process is underway.
    - Explains if anything further needs to be done before the process can start, or
    - Advises the applicant that their application has not been accepted, and on what grounds.

4. Any material that the patient, whilst alive, had indicated was to remain confidential must not be disclosed, except where the law demands it. Any material in the clinical records that is relevant to the purpose specified by the applicant for accessing the records (and which does not fall within the eight categories for non-disclosure defined in the Data Protection Act 1998) is identified and removed to make it available for inspection.

5. Once the relevant extracts have been prepared for inspection, the applicant is advised by telephone and a mutually convenient appointment is made with one of the Clinical Directors for their inspection.

6. The presence of the Clinical Director allows for:
    - Interpretation of any poorly legible handwriting.
    - Explanation of any difficult clinical terminology.

7. Copies are made of any presented items that are requested by the applicant. Any explanations required by the patient are also written down by the attending Clinical Director for the applicant to take away with them for subsequent reference.

8. The applicant has the right to take legal action if they feel that information is being wrongfully withheld.

KATHARINE HOUSE HOSPICE

Copying Letters to Patients

The NHS Plan 2000 stated that patients should be able to receive copies of clinicians' letters about them as a right. It is argued that providing patients with copies of their clinical letters at the time they are created leads to better communication between the clinician and patient, thereby improving patient confidence, understanding and involvement in the management plan. It is recommended that patients with the necessary capacity are routinely asked whether they would like to receive copies of the clinic letters or not.

Letters should not be copied to patients when:

- Patients do not want them.
- The clinician believes that they may cause harm to the patient (e.g. Child protection issues, mental health issues). *The possibility of a patient being upset by a letter does not count as harm in this context.*
- The letter contains information about a Third Party who has not given consent (unless this information was originally provided by the patient), or if the letter breaches the Data protection Act 1998 in some other way (in which case it might become acceptable to send nonetheless if suitable segments are blacked out).
- Special safeguards for confidentiality may be needed (e.g. Genitourinary clinic, abusive marital relationship).
- They contain negative feedback or instructions for better future care directed at the professional recipient for whom the letter is primarily intended. Such feedback should be contained in a separate letter.

There is no legal framework regarding the copying of letters to the carers of patients, except that carers should definitely not receive them when such exclusion has been specifically requested by a competent patient. In other instances, health professionals must exercise their own judgement and consider any guidelines from any relevant Professional Bodies.

If letters are to be copied to the patient, they must:

- Only be copied to patients who have opted in to the arrangement rather than only being excluded from those who have opted out of the arrangement.
- Focus on facts rather than speculation.
- Reinforce and confirm the information that was directly discussed with the patient during the consultation.
- Be written in plain English using simple terms, without becoming so simplified that they become unhelpful to the primary recipient who is normally another health care professional.
- Never simply contain "raw data" such as laboratory reports, or discuss abnormal results that have not first been discussed with the patient.
- Always be sent in envelopes that are marked "Confidential" and addressed to the patient's full name with no initials.

Some patients may have lost their sight, suffer from illiteracy or fail to understand the terminology used in a medical letter. It has been suggested that audio-cassette recordings of letters might help the first group, whilst ready access to a health professionals would help the second and third groups.

Section 5.2 of the Department of Health document "Copying Letters To Patients: Good Practice Guidelines" suggests that, in the absence of a specific clause requiring non-NHS organisations to copy letters to patients in the relevant Service Level Agreement between them and their commissioning body, there is no compulsion for non-NHS organisations to comply with this activity.

Procedure for copying letters to patients

1. Katharine House Hospice is presently under no obligation to participate in the Department of Health initiative described in "Copying Letters to Patients: Good Practice Guidelines". However, it is committed to providing readily intelligible information to patients and their families, including written information that they can take away with them for future reflection or reference.

2. It is routine practice during any outpatient consultation for the doctor or nurse specialist to write down any key points from the meeting for the patient and family to take away with them.

3. Doctors are encouraged to ask patients at the end of the consultation whether they would also like to be sent a copy of the outpatient clinic letter that will be sent to their General Practitioner. Patients who wish to receive copies are supplied with them by post.

References

Independent Healthcare National Minimum Standards Regulations (Department of Health)
National Care Standards Commission Core Standards C31.2, C31.4 and C31.5
http://www.dh.gov.uk/assetRoot/04/07/83/67/04078367.pdf

Protecting and Using Patient Information. A Manual for Caldicott Guardians (NHS Executive)
http://www.dh.gov.uk/assetRoot/04/06/81/36/04068136.pdf

The Caldicott Committee Report on the Review of patient-identifiable information (Department of Health)
http://www.dh.gov.uk/assetRoot/04/06/84/04/04068404.pdf

Data Protection Act 1998
http://www.opsi.gov.uk/acts/acts1998/19980029.htm

Guidance for Access to Health Records Requests under the Data Protection Act 1998 (Department of Health)
http://www.dh.gov.uk/assetRoot/04/03/51/94/04035194.pdf

Access to Health Records Act 1990
http://www.opsi.gov.uk/acts/acts1990/Ukpga_19900023_en_1.htm

Access to Health Records by Patients (British Medical Asociation)
http://www.bma.org.uk/ap.nsf/Content/accesshealthrecords

Copying Letters to Patients: Good Practice Guidelines (Department of Health)
http://www.dh.gov.uk/assetRoot/04/08/60/54/04086054.pdf

NHS Plan 2000 (Department of Health)
http://www.dh.gov.uk/assetRoot/04/05/57/83/04055783.pdf