

PATIENTS' CHARTER

GUIDELINES FOR GOOD PRACTICE

All persons have a right to:

1. health services, appropriate to their needs, regardless of financial means or where they live and without delay;*
2. be treated with reasonable skill, care and consideration;*
3. written information about health services, including hospitals, community and General Practitioner services;
4. register with a General Practitioner with ease and to be able to change without adverse consequences;
5. be informed about all aspects of their condition and proposed care (including the alternatives available), unless they express a wish to the contrary;
6. accept or refuse treatment (including diagnostic procedures), without affecting the standard of alternative care given;
7. a second opinion;
8. the support of a relative or friend at any time;
9. advocacy and interpreting services;
10. choose whether to participate or not in research trials and be free to withdraw at any time without affecting the standard of alternative care given;
11. only be discharged from hospital after adequate arrangements have been made for their continuing care;
12. privacy for all consultations;
13. be treated at all times with respect for their dignity, personal needs and religious and philosophic beliefs;
14. confidentiality of all records relating to their care;*
15. have access to their own health care records;
16. make a complaint and have it investigated thoroughly, speedily and impartially and be informed of the result;
17. an independent investigation into all serious medical or other mishaps whilst in NHS care, whether or not a complaint is made, and, where appropriate, adequate redress;

* Already an established legal right



Published by
The Association of Community Health Councils
for England and Wales

All persons have a right to:

1. health services, appropriate to their needs, regardless of financial means or where they live and without undue delay.

The 1977 NHS Act states:

"It is the Secretary of State's duty to continue the promotion in England and Wales of a comprehensive health service designed to secure improvement –

- (a) in the physical and mental health of the people of those countries, and*
- (b) in the prevention, diagnosis and treatment of illness, and for that purpose to provide or secure the effective provision of service in accordance with this act."*

The right of access to health care regardless of means was fundamental to the establishment of the NHS. Poor law hospitals were taken from the jurisdiction of the local authorities and incorporated into a national health service to protect people from inequalities of regional variations.

A full range of health services must include prevention, diagnosis, treatment, rehabilitation and continuing care at home. It is important for patients to have choice in health services, regardless of where they live because:

- › patients, who have lost confidence in their hospital doctor, can change to a different doctor
- › waiting times can be shortened by going to another hospital
- › a wider variety of treatments and specialist services can be made available
- › people can choose the service they want and so influence the service provided.

Health providers and patient representatives should set targets which they would like to achieve. Patients would then know, for example, the amount of time it is reasonable to wait for appointments, urgent or non-urgent, with GPs or hospitals, and for admission.

2. be treated with reasonable skill, care and consideration.

Patients in NHS care should always be cared for by trained staff. Where junior or trainee staff are providing care, proper supervision is essential.

The General Medical Council's guide on professional conduct states:

"The public are entitled to expect that a registered medical practitioner will afford and maintain a

good standard of medical care. This includes:

- a) conscientious assessment of the history, symptoms and signs of a patient's condition;*
- b) sufficiently thorough professional attention, examination and, where necessary, diagnostic investigation;*
- c) competent and considerate professional management;*
- d) appropriate and prompt action upon evidence suggesting the existence of a condition requiring urgent medical intervention; and*
- e) readiness, where the circumstances so warrant, to consult appropriate professional colleagues."*

3. written information about health services provided, in hospitals, the community and General Practitioner services.

Information about the services available and how best to use them benefits both staff and patients. Such information should be readily available, in basic easy-to-understand English.

It should be comprehensive, covering all NHS and family practitioner services, social services and voluntary organizations.

Where there are residents from ethnic minorities, information should also be available in their languages.

4. register with a General Practitioner with ease and to be able to change without adverse consequences.

Primary care in the UK is based on the continuing care of the 'family doctor' who provides 24 hour comprehensive care, including home visits. In general the system works well, providing continuity of care and personal service.

Matching patient and GP

In view of the personal nature of the GP/patient relationship, it is important for the patient to be able to make an informed choice before registering with a GP, (though this may not be possible in rural areas). Information about the services and facilities provided by different GP practices helps people to make an informed choice. This may reduce the dissatisfaction of people who find their GP does not provide the sort of service they want.

Registering with a GP

In some areas, people have difficulty in registering with a GP. Those who have difficulty are often the



NURSING TIMES

If people participate in their own health care, they are able to make informed decisions.

most vulnerable and inarticulate, (homeless mentally ill, drug users and elderly people). While the Family Practitioner Committee (FPC) protects the right of anyone to register with a GP, and can allocate a patient to a GP in cases of difficulty, the procedures are cumbersome. For people temporarily away from home, there may also be difficulties in registering.

Changing GPs

There are problems for anyone who has lost confidence in his/her doctor and wants to change. The personal nature of the GP/patient relationship may imply that people who want to change must be 'difficult' and therefore unlikely to be welcomed by other doctors. A GP can strike a patient from his/her list without giving a reason, and this can be very distressing for patients.

GPs wishing to strike a patient from their list should be required to seek approval from the FPC and to give reasons for their proposed action. Patients should have the right to be informed of these reasons and comment on them before the matter is considered by the FPC. Transfer sometimes takes a long time. All notes should normally be transferred within one month of changing GPs.

5. be informed about all aspects of their condition and proposed care (including the alternatives available to them), unless they express a wish to the contrary.

Informed decisions can only be made with adequate information. This information should include the alternatives available, the possible effects of no treatment and the side effects of treatment proposed, as well as the effects of diagnostic procedures themselves.

The patient will make a decision based on personal circumstances of which health staff may not be aware. Hospital staff will normally give advice based on the medical evidence. It is, therefore, important that patients have all the necessary information to make a decision.

Where a case conference is held about a patient, s/he should be informed and invited to participate. Consideration should be given to issuing each patient with a written record, similar to the ante-natal card, giving details of tests and treatment given. This s/he would keep themselves.

Some patients do not want information about their condition and treatment. In such cases, the patient should be able to nominate a relative or friend to be given information and participate in the decisions on behalf of the patient.

6. accept or refuse treatment (including diagnostic procedures), without affecting the standard of the alternative care given.

At present a patient who refuses a particular treatment can be discharged from hospital. This may happen only rarely but it can be a serious problem for patients in this position. They should be offered other available services.

People who want to leave hospital against advice should be offered alternative care and treatment in the community.

7. a second opinion.

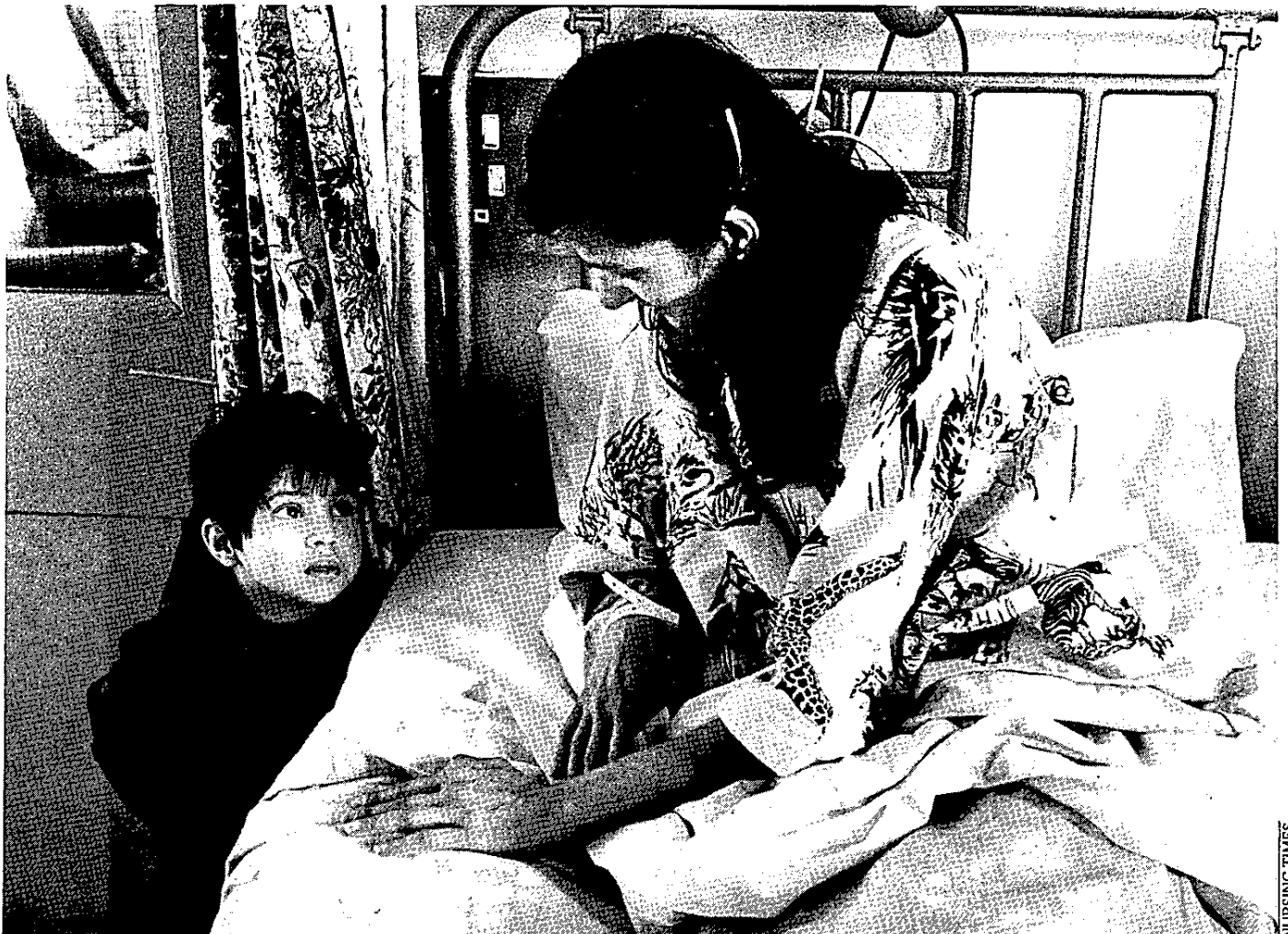
Everyone already has the right to ask for a second opinion and a doctor has a duty to refer a patient for a second opinion when unsure of a diagnosis.

If you want a second opinion, it does not necessarily imply a lack of confidence in the doctor. A patient is faced with major decisions affecting his/her life and wants further advice on which to base this decision. Many GPs or consultants are happy to arrange this.

8. the support of a relative or friend at any time.

The support of a relative or friend during consultations and examinations can help a patient to understand what is being said. Communication problems with staff are two way. Even if staff give full information, patients often experience difficulty in articulating fears and queries in a tense and often brief consultation. The support of a friend or relative can help them understand better what is happening and help them ask questions which are worrying them.

Open visiting should be introduced in all hospitals, where it is not already common practice.



Children should be able to visit relatives and friends in hospital.

9. advocacy and interpreting services.

Advocacy services have been set up to support and represent people who find it difficult to express their own needs and wants, whether because they are mentally handicapped, have language difficulties or are socially or culturally disadvantaged. In the USA all people with a mental handicap have the right to an advocate to represent their interests on the basis of trust and partnership. In the UK the right to an advocate, with access to hospital residents, should be established.

Patients should be informed of advocacy services available, including the assistance that Community Health Councils can give.

10. choose whether to participate or not in research trials and be free to withdraw at any time without affecting the standard of alternative care given.

At present where a research trial is of no benefit to an individual patient, *'a full explanation of the proposed procedure should be given and the patient must feel completely free to decline to participate or withdraw at any stage'*. Where research is intended to benefit the patient, *'although consent should ordinarily be sought there are sometimes circumstances in which it is inappropriate or even inhumane to explain details and seek consent'*. In such cases the patients interests are 'protected' by the District Ethical Committee.

- › People should only be involved in a research trial after they have been given full information about its possible effects.
- › Innovative surgery should only be done after the patient has been given full information about it and its likely effects.
- › District Ethical Committees should all have a patient/ Community Health Council representative to look after patients interests.

11. only be discharged from hospital after adequate arrangements have been made for their continuing care.

The discharge of patients, particularly elderly and mentally ill people, from hospital without prior arrangements causes much hardship and distress. Patients may suffer because of the lack of communication between hospital staff and staff in the community, whether health service or local authority.

Before discharging patients, particularly elderly people, the GP, carers or appropriate community staff – local authority or voluntary – should be notified. Where continuing care is required they should be involved in the decision to discharge.

For all patients, a discharge note to the GP should be sent the same day or given to the patient. Or, the GP should be informed by phone, with a follow up letter.

12. privacy for all consultations.

Privacy of treatment and examination during consultation and examination is essential. This includes both the physical layout of consultation rooms and also the presence of additional outsiders (such as medical students).

- › Physical layout should give privacy so that other people cannot see or hear the consultation.
- › Hospital staff should ask the permission of a patient if they want any other person not directly involved in the consultation to be present (excluding a relative or friend at the request of the patient). Patients now have the right to refuse to have students present, without affecting their care and this should be made clear to patients. If students are present the patient should always be included in the discussion.
- › No tape recording or video-recording should be made without the permission of the patient.



If you understand what is happening, problems may be avoided later.



NURSING TIMES

Life in hospital should be as pleasant as possible.

13. be treated at all times with respect for their dignity, personal needs, and religious and philosophic beliefs.

Treating people, when they are patients, with dignity is important to prevent them becoming passive and 'institutionalised'. Only if they retain their sense of identity will they be able to participate in their own health care. This may require changes in staff attitudes, routines and in the environment. There are many ways in which a hospital routine, whether patients are long-term or short-stay, can be made as close to normal life as possible.

For example, hospitals should:

- › change routines which are organized for staff convenience and can be changed (e.g. toilet routines, early morning waking-up by night staff).
- › provide facilities for shopping, banks, library, phone.
- › allow open visiting and privacy for meeting visitors (e.g. provision of rooms for patients to see visitors in private).
- › provide a more sensitive layout and environment so that there is less noise and light to create disturbance.
- › ask patients how they wish to be addressed and always address them by name.

- › give people the opportunity to make routine decisions about their life including choice of food, bathing times, etc.
- › ensure facilities give access to disabled people so that they can be as independent as possible, when in hospital or attending clinics.

Long-term patients have particular needs for privacy, amenities and storage of personal possessions. The longer the stay, the more important these are.

The needs of religious and ethnic minorities also need detailed consideration, (e.g. translators, special diets, women doctors).

14. confidentiality of all records relating to their care.

This is a right of the patient protected by ethical procedures. However, computerisation may give easier access to medical notes by unauthorised people. This existing right needs re-affirming and more effective technical safeguards introduced.

15. have access to their own health care records.

The wish to inspect one's health care records arises when normal trust and communication has broken down. At present, there is no legal requirement on GPs or hospitals to allow patients to see their medical records. The DHSS encourages DHAs to give access to medical records in advance of legal proceedings. However, this rarely seems to happen. If refused, you must apply to a court of law to order the information to be released.

The Data Protection Act 1984 provided for access by the subject to all automatically processed personal data. The principles are likely to be applied in the future to all records, whether written or on a computer. The Act provided for an exemption in the case of health records and a consultation document on this was issued in 1985. The Inter-Professional Working Group on Access to Personal Health Information (IPWG) made the following recommendations:

'We support the right of patients and clients to have access to all information which is held about them on their behalf. Such access encourages openness and can improve the quality of the record by correcting factual errors and reducing misunderstandings. However, there are some situations in which the unregulated release of the entire clinical or social record may also include information on others who are entitled to have their confidence kept . . . the imposition of an absolute requirement to afford unrestricted access could inhibit health professionals from recording sensitive information or opinions, to the inevitable detriment of patient care; an acceptable mechanism must therefore be devised for the exercise of a proper discretion by the responsible clinician or other health professional. This should provide for [the patient] access to the extent and in the manner judged most helpful by the responsible clinician or an appropriate colleague. Any [patient] who is dissatisfied with this arrangement should then have a right to seek access through an independent health professional of his own choice, practicing in the same discipline or speciality.'

Medical records should be made more accessible to patients on request. If unrestricted access is not acceptable to medical staff, there are ways of overcoming their misgivings. For example, the records may be given to a patient only with a medical adviser of his choice who can assist him/her in interpreting them. If there is good reason for refusing access, the clinician should refer the matter to an independent tribunal with lay members.

16. make a complaint and have it investigated thoroughly, speedily and impartially and be informed of the result.

Complaints procedures are used when the normal channels of communication have broken down. Most complainants want to improve the system so that whatever went wrong will not happen to someone else. Mishandling of complaints can itself force complainants to resort to legal action. There are three major problems about the way complaints are presently handled.

- › Complainants meet hostility, and fear their treatment, or that of their relative, will be affected.
- › Complaints are not generally investigated independently. Complainants often feel, quite wrongly, that they are not investigated at all.
- › Complaints procedures are not always well known or understood by patients.

District Health Authorities and Family Practitioner Committees should automatically inform complainants about the assistance the Community Health Council can give and complainants have the right to be accompanied by a CHC member or officer to any meeting or hearing relating to the complaint.

Every mishap should be investigated, whether or not a complaint is received.

17. an independent investigation into any serious medical or other mishap whilst in NHS care, whether or not a complaint is made, and, where appropriate, adequate redress.

All serious mishap must be investigated. It should not be up to the victim to prove negligence.

At present, the 'victim' of a serious mishap occurring while in NHS care who seeks compensation must prove negligence and take legal proceedings. This is unsatisfactory.

- › It is difficult for the patient to gain access to evidence and witnesses. The delays, often years, increase these difficulties.
- › It is often financially prohibitive to take legal action. Legal aid can be difficult to get. Many solicitors who take on clients have no experience in personal injury and may give wrong advice.
- › The proceedings take years to come to court and be resolved. In the case of injury, compensation is needed immediately to help the victim organize life around the newly acquired disability.

The right to compensation, whether a lump sum or pension, should be established. Part of the compensation at least, should be available within 6 months of the event.

Why patients need a charter

"We believe the NHS should:

- > encourage and assist individuals to remain healthy;*
- > provide equality of entitlement to health services;*
- > provide a broad range of services of a high standard;*
- > provide equality of access to these services;*
- > provide a service free at the time of use;*
- > satisfy the reasonable expectations of its users;*
- > remain a national service responsive to local needs."*

This statement was made by the Royal Commission on the NHS in 1979. The Patient's Charter outlines the basic principles which underlie good relations between patients and health service staff.

Health services are run for us – the users. The

Charter reminds everyone that we have the right to be treated as customers of the NHS. Many of these principles are already practiced in the NHS and the Charter has the support of many staff and professionals as well as users. We hope the Charter will further promote these good practices and the dialogue between health service users and providers.

This is just the start. The Association of Community Health Councils for England and Wales (ACHCEW) welcomes comments from users, carers and health service providers on the Charter and ways of promoting the principles in it. The particular needs of children, elderly, mentally ill and handicapped people, and people from ethnic and religious groups have not been considered in detail. ACHCEW, in collaboration with users and providers of services, plans to develop similar charters to look after their interests.

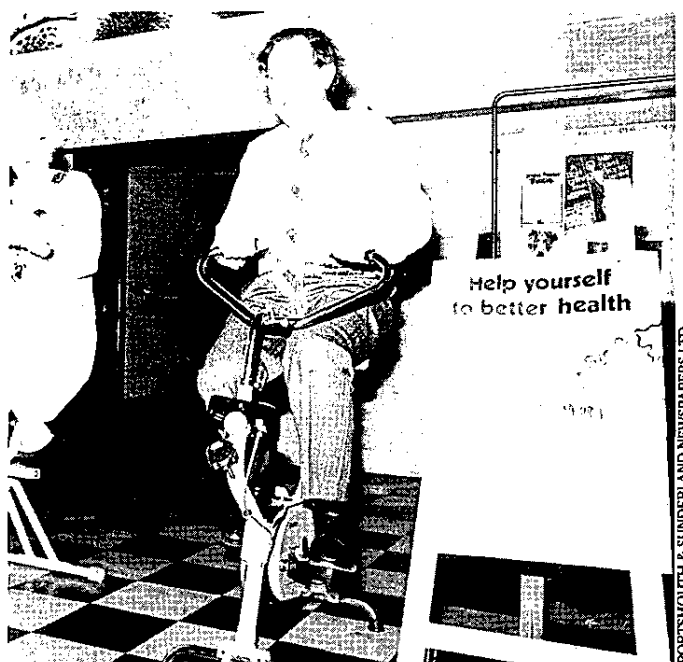
Community Health Councils

Community Health Councils, which were set up in 1974 as a part of the NHS, represent local users in the NHS. Each district has its own Community Health Council. Activities vary according to the needs and interests of the local people. Community Health Councils welcome people to their meetings to participate in their activities. They also often carry out surveys and research to find out local peoples views.

Main activities of community health councils include:

- > advising the NHS on users views about local services, (including matters such as visiting arrangements, waiting times, standard of facilities and care).
- > advising the NHS on plans and developments in local services, in particular on closures or changes in any health service facilities.
- > giving information and advice on health services to the public.
- > assisting people who want to make a complaint
- > promoting the interest and involvement of local people in their own health and the National Health Service.

Most Community Health Councils belong to the **Association of Community Health Councils for England and Wales (ACHCEW)**. ACHCEW acts as a link and information exchange for Community Health Councils. It also represents health service users nationally.



For further information, contact your local
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October 1986