Chapter 14

The NHS: Rights and pledges

We are often told that our health service is the envy of the world and that it costs the country a very large amount of money. At the same time, there is an almost constant stream of stories of patients denied expensive treatments or substandard care on hospital wards. Just what are our rights as patients?

In this chapter I explain these rights one by one, from a right to see our health records to a right to refuse treatment. First, though, a quick word about the organisations that provide NHS care and also their relationship to those that provide closely-linked social care *(defined below)*.

NHS organisation

Although the organisation of the NHS is complex, don't worry too much about understanding who does what. In this book, I use the terms 'health authorities' and 'health bodies' to cover whichever organisation is involved.

In **England,** local clinical commissioning groups (CCGs) commission a wide range of services for patients, from district nursing to ambulance and hospital provision. A national body, NHS England, commissions the services of GPs, dentists, opticians and pharmacists, although CCGs are increasingly involving themselves in this area too.

In **Wales,** NHS health services are both commissioned and delivered by local health boards.

Health boards have performed this dual function in **Scotland** too, but a law passed in 2014 provides for health boards and the local authorities that administer social care to run services more closely together.[1] They have the option of fully integrating some or all of their functions and appointing an integrated joint board to take responsibility. Alternatively, the health board or the local authority can take the lead in any particu-

lar geographical area, performing the functions of both using delegated powers.

In **Northern Ireland,** health and social care services have long been administered hand in hand. Services are delivered on the ground by six health and social care trusts. A separate body, the Health and Social Care Board, which covers the entire province, commissions services from the trusts on behalf of citizens.

How government influences healthcare provision

Our Westminster Parliament and the legislatures in each country of the UK influence healthcare provision in various important ways, not least in deciding the amount of money available to commissioning bodies to buy services from providers such as GP practices.

For potential patients, trying to establish just what care they should receive, the instructions government issues to NHS providers are invaluable. In England, the Department of Health issues 'guidance'. This guidance has more force than the word might suggest: the courts expect health authorities to comply with 'policy guidance'; in other words, it has the power of law. In this book I often quote policy guidance because it can be helpful to patients to know what health providers are expected to deliver in case they are failing to do so.

Sometimes 'practice guidance' is relevant. This is different: it sets out the ways in which the Department of Health considers that a health organisation should go about particular tasks. Health bodies have a legal duty to take practice guidance into account, but do not have to follow it in such an absolute way as policy guidance: if challenged in court, a health body would simply have to explain why it had chosen not to do so. Thus while policy guidance tells an authority what it must do, practice guidance tells it how it should go about doing it.

Elsewhere in the UK, arms of the Scottish government, Welsh government and Northern Ireland Executive perform a similar role in shaping policy and practice on the ground.[2] Contrary to public perception – fuelled by media attention to the differences – official guidance and regulations issued in Edinburgh, Cardiff and Belfast are often very similar to those drawn up by the Department of Health for England.

Health rights

Whichever body provides or commissions their healthcare services, citizens on the ground enjoy a number of rights in the field of NHS healthcare provision. These include:

- the right to receive healthcare services and healthcare equipment free of charge, subject to limited exceptions
- the right to refuse a physical examination and/or treatment
- the right to see their medical records
- the right not to be discriminated against on grounds of race, gender, disability, religious belief or sexual orientation. (Age discrimination has also been introduced, but with limitations, as we see in a moment.)

These healthcare rights apply wherever somebody is living – at home, in a residential or nursing care home, in hospital, prison or a hospice.

In addition to legal rights, the government has made some important pledges on what patients can expect to receive from the NHS. Both the legal rights and the pledges have been brought together in *The NHS Constitution* and the *Handbook to the NHS Constitution*, which accompanies it. Both can be obtained by post or on the internet from the Department of Health.[3] Although these documents are important, they are not well known. They should be.

Clinical commissioning groups in England, the NHS Commissioning Board and the Secretary of State for Health are all required by law to have regard to the principles, values, rights and pledges set out in the NHS Constitution when they are carrying out any of their functions in relation to the health service.[4]

Although written for England, the principles that underlie the Constitution have been accepted by the health administrations in Scotland, Wales and Northern Ireland.

In addition, the Scottish Parliament has passed its own Patient Rights (Scotland) Act 2011 and the Scottish government has compiled a Charter of Patient Rights and Responsibilities. The Charter provides a useful guide and extends patients' rights beyond those provided in the NHS Constitution in the area of guaranteed treatment times *(see below).*

Here are some of the rights and pledges on healthcare provision – many of them set down in the NHS Constitution and the Scottish law and Charter – that can be particularly useful in later life.

Free healthcare

Free provision for all is perhaps the best-known central tenet of the NHS. It means that any NHS service should be free at the point of delivery, unless it has been specially exempted. The NHS Constitution states: 'You have the right to receive NHS services free of charge, apart from certain

limited exceptions sanctioned by Parliament."[5] 'Services' cover not only care and expertise, but also equipment. So your hearing aid or surgeon's scalpel, as well as the work of your surgeon, GP and many more medical professionals, should be free.

What are the 'limited exceptions'? Four years after the establishment of the NHS in 1948, the government of the day realised that the provision of universal free dental care would be far too expensive in a population whose teeth were in poor condition, and it introduced charging for dental treatment. Today, there is special provision for people of modest means who need dental treatment *(set out on page 306).*

Hearing aids are free *(see page 475),* but spectacles and contact lenses are not. Free healthcare does not include blanket provision of free transport to obtain it, and older people often need to make frequent visits to hospital. However, transport to hospital is free in certain circumstances *(as explained on pages 933–4).*

Drugs obtained on a prescription are another of the exceptions that have been made to the general rule. However, prescriptions have been made free for certain groups, including people over 60 throughout the UK. (In Wales, Northern Ireland and Scotland prescription charges have been abolished for everybody.)

Social care

Social care forms the largest single exception to the principle of free care at the point of need. If you have an illness or long-term health condition such as osteoarthritis, you may need not only tests and treatment from healthcare services, but also help with the practical difficulties resulting from your condition, such as in getting dressed or preparing a meal. If you have dementia, you may need someone to keep an eye on you so you do not come to harm. Help provided to cope with such practical matters is called 'social care'.

The need for healthcare and social care thus springs from a common source – illness, disability or general frailty. But while healthcare provision is automatically free, social care is not (although, as we see in Part Seven, various types of social care are, in fact, free).

Another difference is that while healthcare services are administered by the NHS or organisations working for it, social care is the responsibility of local authorities. However, health and social care authorities are expected to work closely together and sometimes services are run jointly.

Patient records

Another important right gives access to an individual's healthcare records, under the Data Protection Act 1998. So all your records – recently computerised ones as well as paper ones, including consultants' letters and the results of tests – should be available to you. The law applies to all information relating to your physical or mental health which is recorded by a healthcare professional, such as a GP, hospital doctor, dentist or physiotherapist, whether working for the NHS or in private practice.

You may find perusal of your medical records useful for the following reasons:

- it provides a means of better understanding your own current medical conditions
- it provides a means of calling to mind past conditions which may recur
- it provides data which may be useful if you are engaged in a dispute over healthcare provision
- it enables you to check that your records are correct
- it enables you to know whether your records contain any instructions with which you might disagree. For example, if doctors have inserted a 'Do not attempt resuscitation' instruction yet you would like attempts made to keep you alive should your heart stop beating, then you could try to get the instruction altered *(see pages 1014–5).*

You do not need to explain why you wish to see your medical records or say which parts of the records you are interested in. Simply telephone your GP practice and ask to be sent an application form to view your records. You will be asked to provide proof of identity (or of your status as a patient's representative). The GP practice manager or another official will be present when you examine your records and you can ask them to photocopy items, for which a small charge may be made.[6] The law says that records have to be provided within 40 days, although government guidance says healthcare organisations should respond within 21 days.[7]

If you are offered online access to your GP records, you may receive only a summary covering the medication you are taking, your allergies and any adverse reactions to drugs. The Patients Association publishes a useful, free guide called *How to Obtain Access to your Medical Records.*

Waiting times

The NHS Constitution pledges that patients should not have to wait for longer than a set period in certain situations. These include the following:

- When a patient arrives in Accident and Emergency (A&E), they should not have to wait for more than four hours until they are admitted to a ward, discharged from the hospital or transferred (the Constitution does not say where to).
- If a patient has an operation cancelled for non-clinical reasons on or after the day they are admitted to hospital, including the day of surgery, they must be offered another binding date within 28 days. Or their treatment must be funded at the time and hospital of their choice.
- A patient must be seen by a cancer specialist within a maximum of two weeks from a GP urgent referral where cancer is suspected.[8]
- A patient who is referred for investigation of breast symptoms must not wait longer than two weeks to see a specialist, even if cancer is not initially suspected.
- A patient must not wait longer than 31 days from diagnosis to their first treatment for all types of cancer.
- Any consultant-led treatment for a non-urgent condition must start within a maximum of 18 weeks from referral.

In the last two cases, the Constitution lays down that if the NHS body that commissions and funds the treatment is unable to deliver it itself, it must take all reasonable steps to offer a suitable alternative provider.[9]

Patients in Scotland also enjoy a right to another maximum waiting time. The Charter of Patient Rights and Responsibilities says that any planned treatment which a doctor has agreed with a patient must start within 12 weeks and gives as examples of treatments covered by this guarantee: hip or knee replacements, hernia surgery and cataract surgery. The Charter further provides that if a health board cannot provide treatment within that time, it must explain the reasons for this, give the patient information about how to make a complaint and take steps to ensure they start their treatment at the next available opportunity, taking account of other patients' clinical needs. Some treatment is exempt from this treatment-time guarantee, including organ transplantation and assisted reproduction.[10]

Treatment in Europe

If your treatment on the NHS will become available only after an unacceptable delay, you could require your NHS body to pay for it in another European Economic Area (EEA) country or Switzerland. Under a European Union regulation, if your NHS consultant considers that you should be offered a particular treatment on the NHS and the NHS cannot provide it without 'undue delay', and that treatment is available from a state provider in an EEA country or Switzerland, you can apply to be treated there, with your health costs met by the NHS.[11] Ask for form S2. The NHS Constitution and Scotland's Charter of Patient Rights and Responsibilities confirm this right.[12]

A court case in 2006 established that health authorities are not permitted to refuse to fund treatment elsewhere on the grounds that they do not have the cash to pay for it.[13] However, bear in mind that if nationals in the member state where you wish to obtain treatment themselves have to pay a proportion of that treatment, say, 20 per cent, you will be expected to do so too. Do also be aware that if the operation goes wrong, you will probably have to pursue any complaint in the country in which the treatment took place.

Consent

As patients, we do not have the right to insist that a particular treatment or test be offered to us by the NHS. However, we do have the right to refuse any medical treatment or examination we are offered, unless we are unconscious or have been detained under mental health law. In normal circumstances, any medical professional who gives us a physical examination or treatment without our consent is acting unlawfully. When we go to see our GP, our implied consent to the tests and treatment they offer us is assumed, and when we have an operation, a hospital will ask for our written consent. But it is important to be aware that we can withhold consent at any time.

The rules on consent are set out in the Department of Health's publication *Reference Guide to Consent for Examination or Treatment*, issued in 2009. This begins by establishing that:

> It is a general and ethical principle that valid consent must be obtained before starting treatment or physical investigation, or providing personal care, for a person. This principle reflects the right of patients to determine what happens to their own bodies, and is a fundamental part of good practice.

Fundamental to obtaining consent is acquainting patients with facts so they can make an informed decision. So expect your doctor to ensure that you understand:

- ✓ the nature, benefits and risks of any investigation or treatment they are offering
- ✓ the nature, benefits and risks of any alternative investigation or treatment
- ✓ the consequences of not receiving any treatment

If you have difficulty in communicating, perhaps because of sight or hearing problems or limited grasp of English, expect your doctor to take all necessary steps to ensure that you can comprehend what they are saying, including writing things down if necessary.[14] If a health professional fails to obtain proper consent and you subsequently suffer harm as a result of treatment or a physical examination, failure to explain adequately may be a factor in a claim of negligence against the doctor or nurse involved.

Patients can also refuse to participate in teaching if they wish. Any consultant who breezes up to a patient's bed with an entourage of students and asserts: 'Mr Smith, you don't mind, do you?' should know that is bad practice. Any patient should be consulted properly beforehand and given the opportunity to refuse if they so wish. There are strict rules on seeking patients' consent for participation in research.

Some people are so certain that they do not wish to receive certain forms of treatment that they have drawn up an 'advance directive to refuse treatment' (similar to a 'living will'). This directive is a statement of wishes to refuse specified forms of treatment in the event of being unable to give consent at the time treatment is necessary *(I discuss it on pages 1017–20).* Plainly, if you make an advance directive, you should also ensure it will be easy to find in an emergency.

Consent for people with impaired mental powers

You may be tempted to skip this section – don't! Any of us at any moment could become incapable of giving consent for a medical examination or treatment because we are unconscious or delirious, we have had a major stroke or other brain injury, or we have developed dementia. In this situation, when the considered consent of the patient cannot be obtained, any healthcare professional must take whatever action they or a medical team considers would be in the best interests of the patient.[15]

When working out what these best interests might be, doctors and nurses must take into account the person's past and present wishes and

feelings, the beliefs and values that would be likely to influence their decision if they had mental capacity *(defined in the Glossary),* and any other factors that would be likely to influence their decision. They must also seek the views of certain other people before they can go ahead, if is practicable and appropriate to consult them. A key person here is any attorney with powers to take proxy decisions in the health field whom the person had previously appointed, *as explained on pages 782–5*.

Any patient in England and Wales who lacks the mental capacity to make a decision about whether to accept significant medical treatment such as major surgery or to convey their decision must be given a special 'advocate' to represent their interests. In Scotland, any adult with a mental disorder is entitled to be given an advocate.

In 2016 a new law on mental capacity for Northern Ireland was passed. However, it is unlikely to be brought into effect for several years *(see page 750).* In the meantime, you could expect its provisions (which are similar in many respects to the mental capacity legislation for England and Wales) to guide best practice. *I discuss the rules governing consent for people who lack mental capacity in more detail in Chapter 33.*

Patient choice

A patient cannot fully exercise their right to give or withhold consent without understanding the implications of refusing or accepting a test or treatment that a doctor is offering. So patient choice is inextricably bound up with patient consent.

The NHS Constitution places patient choice centre stage, declaring: 'You have the right to be involved in planning and making decisions about your health and care with your care provider or providers, including your end-of-life care, and to be given information and support to enable you to do this.'[16]

This right to choice so firmly proclaimed by the government poses a fundamental challenge to the paternalistic doctor-knows-best attitude. However, genuine shared decision-making and choice pervading every aspect of patient care is only going to materialise if patients seize the opportunity to ensure that it does. You may need to prompt, even over apparently minor matters. If, say, your doctor says they are sending you for a consultation at a foot clinic, make sure they consult you about which hospital or clinic will be involved. The facility the doctor has in mind might be in a location you would find inconvenient, and you may regret not having discussed alternatives when you face a half-an-hour wait for the bus to take you there.

Another example: if you object to the method by which medication is delivered to you – perhaps large tablets rather than liquid – ask your doctor about the alternatives and expect to be fully involved in the decision that will be made when the prescription is written. The possibilities for involving patients in choice, whether over decisions made by doctors, nurses, pharmacists or other professionals, are endless. Here are three areas in which you may care to exercise choice.

Choice of GP

While we have no choice of, say, social worker, we can choose our own doctor. As GPs are the first port of call when we have an ailment and are also the gateway to much healthcare provision, wise choice of GP practice is very important. The NHS Constitution states, 'You have the right to choose your GP practice, and to be accepted by that practice unless there are reasonable grounds to refuse, in which case you will be informed of those reasons.'[17]

Particularly in inner cities and rural areas, the most favoured GP practices are likely to have full lists and to operate tight geographical boundaries. However, if you live within a practice's area, it must accept you, unless its list is full. Practices are allowed to turn down prospective patients within their area only if they close their lists to any new patients. This rule is designed to prevent practices cherry-picking patients and rejecting those with multiple health needs likely to involve the practice in much time and trouble.

If you are choosing a GP practice, go and talk to the practice manager and ask around; in England, the website MyNHS allows some comparisons to be made.

If you prefer to see one doctor in the practice rather than others, say so. The NHS Constitution states that, 'You have the right to express a preference for using a particular doctor within your GP practice, and for the practice to try to comply.'[18]

Named GP for people aged 75 or over

Since 2014, the contract in England between the government and GPs has said that patients who are aged 75 or over should be assigned a named GP in their practice who will take lead responsibility for ensuring they receive whatever services they need from the practice. This GP will not always provide services – a patient could still be seen by someone else, such as a member of the practice with a particular specialism. (A named care coordinator, who might be the named GP or another professional, could also be brought in.)[19]

The GP contract says that patients should be simply informed of their allocation to a particular GP. If you have built up a good relationship with another GP, you may not wish to change to a GP to whom the practice has assigned you. If so, object, quoting the pledge in the Constitution above. The NHS tells GP practices, 'Where the patient expresses a preference as to which GP they have been assigned, the practice must make reasonable effort to accommodate this request.'[20]

Out-of-area patients

Patients in England can, in theory at least, register with two GP practices. The government has introduced the option for practices to register patients from outside their geographical boundaries, without any obligation to provide those patients with home visits.[21] Although this facility is of most obvious benefit to people who commute long distances to work and whose chances of seeing a GP during practice opening hours are minimal, the option is not confined to working people. So if, for instance, you often stay in another part of the country, you could also consider applying to take advantage of this opportunity.

Choice of specialist healthcare provider

As choice is a fundamental tenet of the NHS Constitution, patients throughout the UK should expect choice in the specialist to which a GP or hospital doctor refers them.

In England, a system called Choose and Book has been set up to enable patients to exercise choice in this situation. It allows patients to choose a hospital for referral anywhere in England. This could be in their own locality or far away; it could be an NHS hospital or a private hospital which offers the NHS service required. The website chooseandbook.nhs.uk provides information to enable people to make comparisons between hospitals.

Choose and Book does not cover treatment requiring speed, such as for chest pains and suspected cancer. Also, the system allows patients to choose a hospital, but not the particular staff in that hospital. So it can be useful in allowing somebody to choose to go to a hospital with low rates of hospital-acquired infection or expertise in a particular area, but it does not provide a guarantee that they will be seen by the consultant of their choice, although there is no reason why they should not make a request to be seen by a particular person. Choose and Book includes both physical and mental health services. *(I examine Choose and Book in more detail in the chapter on staying in hospital, on pages 905–6.)*

Personal health budgets

An increasingly popular way in which care for people with long-term chronic conditions is being funded in England is through personal health budgets. The principle of free healthcare is retained, but the health authority gives the patient or their representative a sum of money to buy the healthcare services it would otherwise have organised for them, thereby giving them greater choice over the way in which the money allocated for their care is spent.

Personal health budgets are not given for routine aspects of NHS provision, such as emergency treatment at A&E or a consultation with one's GP, but for the treatment of ongoing illnesses, palliative care and NHS Continuing Healthcare *(explained below)* – situations in which choice can be exercised across a range of types of treatment, such as fitness classes, physiotherapy, psychological therapy and attendance at a day hospice. A health professional discusses with the patient or their representative the services that could be commissioned and their cost. A support plan is then drawn up, setting out how the money will be spent; this must be agreed by both parties before the budget is handed over.

One field in which personal health budgets are firmly established is NHS Continuing Healthcare. This is a form of NHS funding allocated to a small number of people (about 60,000 people in England, for example) who need a great deal of care on account of a serious medical condition or conditions, or because they are terminally ill. It provides free social care regardless of means, as well as healthcare, and the amount of money given per patient can run into tens of thousands of pounds every year. The care involved can be provided in an NHS facility, a nursing home or the home of the patient or a friend or relative.

It can be especially helpful to exercise choice in the form in which NHS Continuing Healthcare is received, *(as we see on pages 963–8).* NHS England has said that people awarded NHS Continuing Healthcare have a right to have a personal health budget (though this is not a legal right), and that, 'People with long-term conditions who could benefit should have the option of a personal health budget'.[22]

If you think you would like a personal health budget, raise the matter with your GP or hospital consultant. It may not have occurred to them to offer you one. Mental healthcare is included. The website Peoplehub.org.uk publishes video stories of people who have experience of using personal health budgets to cope with depression, motor neurone disease, Parkinson's disease and dementia, and to manage an NHS Continuing Healthcare budget.

Whatever the area of healthcare for which you are offered or ask for a budget, make sure that it does not leave you short-changed. Cash-strapped health bodies may be tempted to provide less than is necessary to buy the services and equipment recipients need, in the hope that they will top up the budget out of their own resources. If clinical commissioning groups do this, they will be flying in the face of the central tenet of the NHS that healthcare is free to those who need it. So make sure your personal health budget is large enough to cover the costs of the healthcare you should be receiving. Health bodies should not be trying to introduce charging for services by the back door by declining to give people enough money. Also, don't allow a personal health budget to be foisted on you, perhaps to relieve NHS officials of the task of organising your care. As the NHS has said, 'Personal health budgets … will always be optional for patients.'[23] *(See also page 966.)*

The right to treatment

You cannot demand that a doctor gives you a particular treatment: it is offered to you if a doctor considers that it might help you and would not be futile. However, a well-established feature of the NHS, restated in the NHS Constitution, is that patients have the right to the drugs and other forms of treatment that the National Institute for Health and Care Excellence has recommended for use in the NHS, so long as their doctor says they are clinically appropriate for them.[24]

NICE

The National Institute for Health and Care Excellence, or NICE, is an organisation based in London which commissions teams of experts from many disciplines to draw up detailed guidance on the way in which particular medical conditions should be treated. The treatment it recommends includes anything from medication to physiotherapy and surgery to nursing care.[25] NICE pronouncements often attract criticism if NICE has declined to recommend a particular drug for use in the NHS. You may therefore be inclined to dismiss NICE guidance in general. Please do not. It can be extraordinarily useful when working out what treatment you can expect to obtain.

Once NICE clinical guidance is published, health professionals (and the organisations that employ them) are expected to take it fully into account when deciding what tests and treatments to offer people. NICE guidance should be followed by both medical professionals and the organisations that employ them in whatever location NHS healthcare is

provided. This could be a general, specialist or community hospital, a patient's home or a residential or nursing care home.

However, NICE clinical guidance does not replace the actual knowledge and skills of individual health professionals who treat patients; it is still up to them to make treatment decisions in consultation with the patient and/or their representative *(or one of the other categories of consultee listed on page 782).* In other words, a patient's right to treatment recommended by NICE is not absolute: it comes with the proviso 'if the doctor considers it is clinically appropriate'. So, while doctors are expected to take NICE guidance into account when coming to decisions about individual patients, they are not forced to prescribe any particular drug or treatment. However, if a doctor denies a patient a drug or other treatment recommended by NICE and is taken to task, their health organisation would have to demonstrate why the doctor did not consider it was appropriate for that particular patient's condition.

NICE guidance published to date covers conditions such as diabetes, glaucoma, heart failure, high blood pressure, Parkinson's disease, prostate cancer and the wet form of age-related macular degeneration. *(I refer in detail to NICE guidance on dementia, depression, falls, urinary continence and strokes in Part Five.)* Since 2013, NICE has been also drawing up guidelines in the field of social care.

NICE guidance is available on the internet. It is worth noting that although NICE publishes guidance for the general public, the clinical guidelines issued for professionals (released in full and summary forms) are often more useful if you are checking to see that you are receiving the best treatment you can reasonably expect.

NICE clinical guidance operates to varying degrees over the UK. It applies in England and Wales. In Northern Ireland, the Department of Health, Social Services and Public Safety assesses guidance published by NICE and decides whether it should be implemented; much NICE guidance has been so endorsed. In Scotland, a similar body to NICE, Healthcare Improvement Scotland, examines NICE guidance and often recommends its adoption or that of a group of healthcare experts called the Scottish Intercollegiate Guidelines Network (SIGN). SIGN's recommendations are often very similar to NICE's. The Patient Rights (Scotland) Act 2011 says that the healthcare citizens receive must be based on current clinical guidelines.[26]

Tests and treatments required under the GP contract

The GP contract, agreed between doctors' representatives and the NHS every year, forms the basis on which GP practices operate. It sets out what

GPs have to do in return for their payments from the state. The contract was agreed in 2004 and it is modified slightly each year. It is divided into a core contract, which sets out the essential services that practices must provide in return for a basic payment, and other services which GP practices can choose to offer their patients. Since 2013, there have been separate contracts for England, Scotland, Wales and Northern Ireland, but they tend to be similar to the one described here for England.

Annual health checks for patients over 75

One element of the core contract is a requirement that all patients aged 75 and over should be given a general health check every year by their GP practice. This check is a general consultation, 'In the course of which [the practice] shall make such inquiries and undertake such examinations as appear to be appropriate in all the circumstances'. It should take place in the patient's home if their medical condition makes it inappropriate for them to visit the surgery. This annual health check is in addition to normal consultations and to the appointment of a named doctor for patients aged 75 and over described above.[27]

One advantage of a general health check – a sort of MOT – is that medical conditions previously unknown to the doctor or the patient can be picked up, for instance late-onset type 2 diabetes. A study of 40 GP practices in Nottinghamshire found that as many as a quarter of annual checks for older people carried out revealed a problem previously unknown to the patient's doctor.[28]

The catch is patients have to request the health check – GPs are not instructed to offer it automatically. This is a shame, because many people will be completely unaware of the facility, yet their GPs are receiving payments from government on the assumption that it is being provided. If you think this general health check would be of benefit to you, ask for it. It is unlikely it would not be.

You may need to press. A survey published by the British Geriatrics Society (an association of medical professionals interested in the care of older people) uncovered the shocking statistic that as many as 68 per cent of residents in care homes were not receiving a regular planned medical review by their GP in 2010. Yet the vast majority of people who live in care homes are well over 75 years old.[29]

Medical condition payments

On top of the core payment for essential services, practices can opt to try to meet targets in another part of the contract, called the Quality and Outcomes Framework (QOF). This singles out certain (not all) medical

conditions and, for each of these, sets out a system of steps GPs should take to address the condition; compliance with each of these attracts a separate payment for the GP practice.

For each of the selected categories of ailment, the practice must assemble a register of all patients in the practice who are suffering from it. For several conditions, this register forms the basis of a complex tier of further standards and rewards. Thus for diabetes, different tiers of reward are given if a practice has given particular tests to patients with the condition, as well as rewards for particular treatments. A complex panoply of rewards is also offered for tests and treatments for asthma, chronic obstructive pulmonary disease (such as emphysema), coronary heart disease, epilepsy, and stroke and transient ischaemic attacks.

However, by no means all of the common chronic conditions of later life have been selected for the QOF incentive system. GPs are expected to give the best possible treatment to their patients with other conditions too, but obviously there is a danger that the basic tests and treatments required under QOF do not spring to mind so readily for other conditions or that GPs do not always devote as much time and energy to those for which QOF offers no or only a very basic reward.

This danger was borne out by a study of the quality of care for 13 different conditions in England in 2008. Eight-and-a-half thousand people over 50 were interviewed about the care they had received. While 75 per cent of them reported that they had received good care for conditions which were covered by the QOF, the figure was only 58 per cent for non-QOF conditions. Some conditions performed particularly badly: for example only 29 per cent of patients who were interviewed who had osteoarthritis (still not within QOF) seemed to be receiving good care.[30]

In Part Five I discuss what you might reasonably expect from a GP if you suspect you may be suffering from a few of the most common conditions of later life. The majority of the conditions I discuss are either not covered or covered only in a very basic way by the Quality and Outcomes Framework.

Services from pharmacies

Like GP practices, pharmacies also have their own contract which lays down the essential services they must provide in return for payment from the NHS. These services include ones we might expect, such as the dispensing of medicines, but others which can also be invaluable.

Pharmacies must provide **support for self-care services.** These are aimed not only at people who are trying to care for themselves, perhaps with a long-term condition, but also for unpaid carers. Both groups

must be provided with, 'Appropriate advice to help them self manage a self-limiting or long-term condition such as diabetes or osteoporosis, including advice on the selection and use of any appropriate medicines'.[31] Pharmacists must also ensure that carers and people managing a long-term condition are given information by pharmacies about the treatment options they have, including non-pharmacological ones.

As another essential service to the public, pharmacies must provide **advice on healthy living.** If you have a question about diet or exercise, you could ask your pharmacist.

All pharmacies are also required by their contract with the NHS to signpost people who need help that cannot be provided by the pharmacy to other providers of health and social services and support organisations.

Pharmacies must also offer a **minor ailments service,** in other words, they must offer advice and if necessary medication on such ailments as:

- skin conditions, including mild acne, mild eczema and athlete's foot
- coughs, colds, nasal congestion and a sore throat
- minor cuts and bruises
- constipation and haemorrhoids (or piles)
- hay fever and allergies
- headaches, earache and back pain
- indigestion, diarrhoea and thrush
- warts, verrucas, mouth ulcers and cold sores

There are also so-called Advanced Services that pharmacies can choose whether to provide.[32] Advanced Services attract additional funding from the NHS. These include the **New Medicine Service.**

When we are given a new medicine, many of us stop taking it within a short time because of side-effects or difficulties in taking it. The New Medicine Service is designed to help patients understand a newly prescribed medicine for a long-term condition, so that they take it as the doctor intended. The consultation should take place in a private area and be followed by a subsequent meeting or phone conversation in about a fortnight and then a final consultation between three and four weeks after starting the medicine. If a significant problem persists, the pharmacist may refer the patient to their GP.

Another service which pharmacies may sign up to provide is **Medicines Use Reviews.** When a pharmacist conducts such a review, they sit down with a patient in a private consultation area, assess the patient's use

of their existing medicines and attempt to identify any problems they may be experiencing. The Review can be conducted regularly, say, every year, or when a significant problem with someone's medication comes to light or when a drug is being dispensed. The pharmacist can refer any issues on to the patient's GP.

Medicines Use Reviews and the New Medicine Service are potentially valuable and it is certainly worth asking for a consultation if you think it might help you. Not all pharmacies offer these services: if your pharmacy does not, ask which pharmacies in your area do.

We have already noted *(see page 16)* that drugs have a different effect on the body as we grow older. Changes to the liver and kidneys which are an inevitable part of the ageing process mean that we become more sensitive to drugs, because our body cannot process them as effectively as it could when we were younger. This has implications for dosage. Also, older people are more likely to develop side-effects to drugs. These can of course be harmless, but can also be dangerous. Some drugs can increase the risk of falls, for instance *(see page 390)*.

Expect the following questions to arise during a Medicine Use Review or in a subsequent consultation with your GP:

- ✓ Are my drugs continuing to help whatever condition they were selected to address? One study of medication reviews for care home residents revealed that in nearly 50 per cent of cases the recommendation was that a drug should be stopped; in an astonishing two-thirds of these cases, there was no stated reason for the medicine having been prescribed in the first place.[33]
- ✓ Are the drugs being delivered in the correct form? If they are being given as tablets, might a liquid form or patch suit me better?
- ✓ Should anything be done to help me take my drugs? For instance, should the pharmacist offer a dosette (a device with little compartments indicating time and day of the week)?
- ✓ Are any of the drugs, both those newly prescribed and those that have been taken for some time, giving rise to undesirable side-effects? Can anything be done about these side-effects? Or should a different drug be selected?
- ✓ Are there any drugs that might be of benefit that are not at present being prescribed?

Pharmacists may also sign up to provide an **Appliance Use Review Service,** which can be conducted in a private consultation area or in the patient's home by the pharmacist or a specialist nurse. It would help people having difficulty with using a stoma, for instance.

In future, pharmacies are likely to become more and more involved in health promotion and prevention by encouraging people to look after their own health and to self-manage ongoing medical conditions, such as diabetes, high blood pressure and asthma. As more and more people wear telehealth monitors *(see pages 495–6),* pharmacies are likely to play a key role in helping people to interpret the results. They are also likely to become more involved in NHS health checks for the likes of skin cancer, respiratory disorders, diabetes, high blood pressure and an irregular pulse rate.

Respect for human rights

The NHS has a legal obligation to respect every patient's human rights. Parliament has decreed that it is unlawful for a public authority to act in a way that violates one of the human rights set down in the European Convention on Human Rights.[34] These rights include:

- Article 2: the right to life
- Article 3: the right not to be subjected to inhuman or degrading treatment
- Article 5: the right not to be deprived of one's liberty, except in clearly defined circumstances
- Article 6: the right to a fair hearing or trial
- Article 8: the right to respect for one's private and family life, home and correspondence
- Article 14: the right not to be discriminated against in the enjoyment of any other Convention right

The legal duty to respect these rights applies not only to public bodies (such as the NHS and the social services departments of local authorities) but also to organisations performing a public function. These might be a private hospital carrying out work for the NHS, or a GP practice, or a private care home looking after people through a contract with the NHS, or a housing association fulfilling housing functions on behalf of a local council. If any of these bodies fails to provide someone with a fair hearing in a dispute or subjects them to degrading treatment or fails to respect their private life, for example, it can be taken to court.

The more harm the breach of somebody's human rights has caused, the stronger the case – including for compensation. In mounting a defence for a breach of a human right, it is not permissible for a public body (or one carrying out a public function) to excuse its behaviour by saying it did not have sufficient money to act in the way it should have done or that its actions arose out of ignorance rather than deliberate intent. In other words, a hospital ward could not say that it lacked the cash to employ sufficient numbers of staff to ensure that patients were not left in urine-soaked sheets, nor that staff were ignorant of the way in which the human rights of patients should be upheld. What matters is that somebody has suffered harm because their fundamental human rights have been breached. However, the courts are reluctant to direct public authorities to take action where the allocation of resources is involved. So it is not always possible to force an authority to provide a particular service or treatment, unless someone is being mistreated or suffering harm.

The outlawing of discrimination

Since the European Convention on Human Rights was drawn up and the British Parliament required public bodies to comply with it in 1998, further thinking has refined just what the protection of an individual's human rights should mean. Public debate and campaigning in Britain have focused on safeguarding the position of people who might be discriminated against, such as those with a disability. The Equality Act 2010 addresses the protection of human rights in a different way from the European Convention; both approaches have proved very useful.

The Equality Act, which applies in England, Wales and Scotland, forbids any provider of goods and services whether private or public from discriminating against someone or treating them differently from other people in a similar situation because they possess a so-called 'protected characteristic'. These characteristics are:

- the presence of a disability
- their age
- their race
- their religion or belief
- their sex
- their sexual orientation
- their gender reassignment
- their being married or in a civil partnership

- their being pregnant or being a parent[35]

This means that a hotel, bank or betting shop as well as a hospital could be penalised by a court if it does not make its goods and services equally available to say, people of a particular race or religion or age, unless the service provider in question could persuade a court that its action (or inaction) is justified.

In a case of which I became aware a deaf man had to wait three weeks in a hospital in Scotland for his health board to provide the sign language interpreter he needed. The delay was unfortunate, but an interpreter might never have been forthcoming had he not enjoyed the legal right not to be discriminated against when services were provided. For the Equality Act (together with the rules on gaining patient consent) mean that any doctor providing a patient with the information they need to make an informed consent to treatment must take steps to ensure they are not discriminated against because of any disability. The doctor must do what they can to ensure the information is available in a form in which the patient can absorb it and that they can express their views. If the patient cannot speak English, the doctor would need to provide an interpreter. It is the forbidding of discrimination against people on grounds of race and disability that has prompted the provision of information about services in different languages and in large-print, audio and Braille formats. *(See also the so-called public sector equality duty on page 692.)*

Age discrimination

As we have just seen, age is one of the protected characteristics under equality law in Britain. So it is against the law to treat someone less well when goods or services are being provided to them because they are of a certain age (whether they are young or old), whether the provider is a golf club or a GP practice. However, protection again age discrimination is not absolute – certain limitations have been introduced.

The government has told doctors, nurses and other professionals, as well as the commissioners and providers of health and social care services, that they, 'Can continue to treat people differently because of their age. However, they will need to show, if challenged, that there is good reason (or objective justification) for that different treatment.'[36]

What does this mean in practice? Take the age cut-off points in the mass screening for particular diseases. These are often difficult to defend on medical grounds, so they might be overturned by court decisions in the future.

Women are sent routine invitations for breast screening every three years only up to the age of 73. Yet 40 per cent of breast cancer cases occur in women over 70, and women over 80 are the group most at risk.[37] Women over 73 should therefore ask for breast screening themselves.

There are many other ways in which you might encounter age discrimination in healthcare provision. Your doctor suspects you may have Parkinson's disease but declines to refer you to a specialist when they would have referred a younger person; they could be guilty of age discrimination. If your local health body refuses to provide you with a physiotherapist within a certain period, yet provides such a service to a younger person with the same medical condition as yours, that too could constitute age discrimination. Or if you suffer a major stroke and the nursing home in which you are living fails to summon emergency help, it could be guilty of age discrimination, since a stroke in someone of any age should be treated as a medical emergency *(see pages 349–52).*

If you are concerned that you have been discriminated against on grounds of age, the question you need to be able to answer in the affirmative is: has the health professional or health body treated me less favourably than it would have treated somebody else in a similar situation but of a different age?

How can you tell? Well, to start with, you could have a look at the NICE guidance that sets out the tests and treatment that health bodies and professionals should provide for many different medical conditions *(see pages 289–90).*

The follow-up question must then be: is there any good reason why I should have been treated differently? A doctor might argue that they declined to offer a patient a particular treatment because they thought it would be futile. For instance, they might decide against trying to restart somebody's heart if it had stopped beating because they thought the procedure would not work because the person was too weak. However, a doctor must not base their clinical decision on the patient's chronological age. None of us ages in precisely the same way, as we discovered in Chapter 1. The more refined approach, which a doctor should adopt, is to look at somebody's 'biological age' *(as explained on page 12).* In other words, a doctor must not refuse to attempt resuscitation simply because their patient is very old.

If a health professional or organisation denies you a test or treatment, referral to a specialist or provision of a type of NHS funding, that decision has affected you badly and you think it was based on your age and could not be objectively justified, ask the person responsible to reverse or amend the decision. If you fail and need speedy action, consider the

steps to resolve urgent healthcare problems outlined in Chapter 15. If immediate action is not called for, consider lodging an official complaint *(see pages 336–41)* and/or taking a claim of age discrimination to your local county court (in England or Wales) or sheriff court in Scotland. If you win your case in court, the judge or sheriff could make a ruling that the discrimination should be put right, so you would be given the test or treatment which had been withheld on grounds of your age. The judge or sheriff could also award you compensation, including for any hurt feelings. Mention that you might lodge a complaint or go to court, thus showing awareness of your legal rights, could work in your favour, even if you would not in fact seriously consider going that far.

Before you take steps to pursue the matter in court, talk to your local Citizens Advice or a helpline advisor of the Equality Advisory Support Service *(see page 691),* as you would have to pay a court fee to make a claim (though you may be eligible for legal aid), and if you lose your case you may have to pay the legal costs of the other party. The Equality and Human Rights Commission publishes guidance on how the law should be complied with and what might be deemed to be unacceptable discrimination, *as explained on page 689.*

If you plan to take a claim of age discrimination to court, make sure you leave yourself sufficient time. The Equality Act lays down a time limit for making a claim of six months from the date of the alleged act of discrimination to which a claim relates. If you first try to pursue the matter another way, perhaps as an NHS complaint, you might run out of time. Fortunately, the legislation allows for discretion on the part of the court, saying that a case may be heard after such period as the county court or sheriff 'thinks just and equitable'.[38] But note: *may*.

No legislation barring age discrimination in Northern Ireland had been drafted at the time of writing.

I also explore the use of the Equality Act in the field of disability discrimination on pages 687–92 and in age discrimination in the workplace on pages 882–3.

National Service Frameworks for Older People

Quite apart from the Equality Act, there are older anti-age-discrimination directions which can prove useful.

The Welsh Assembly published a *National Service Framework for Older People in Wales* in 2006. This sets out standards which the Assembly expects healthcare providers to attain. Unequivocal in its disapproval of discrimination on the grounds of age in the provision of health services, the first standard, called 'Rooting out Age Discrimination', states:

'Health and social care services are provided regardless of age on the basis of clinical and social need. Age is not used in eligibility criteria or policies to restrict access to and receipt of available services.'[39]

If you feel you are being denied a drug or other treatment or examination on grounds of age in Wales, then you could challenge your doctor or health board, if necessary quoting Standard One.

Standard Two, called 'Person-centred Care', could also be useful. It states: 'Health and social care services treat people as individuals and enable them to make choices about their own care.'[40] In other words, an older person should not be treated in a way which does not treat them as an individual. If, for instance, you have been admitted to hospital after suffering a stroke and a doctor proposes to send you for acute care to a geriatric ward rather than the stroke ward where you think you would receive better treatment, discuss the matter with them and mention this standard if necessary. *(See also pages 358–9.)*

Not only does the Framework set general standards which the Assembly considers the health service (and social services) should reach in areas of key importance to older people, it also contains detailed recommendations for best practice in particular areas, including the use of medicines, falls and bone fractures, mental health (including depression and dementia), and the care of older people in hospital. The Framework is available by post from the Welsh Assembly Government and on its website.

Although this National Service Framework does not, strictly speaking, apply to England, Scotland or Northern Ireland, it would be difficult for a health organisation in these places to argue that the injunctions and standards set out for Wales should not also apply to them. In fact, a similar and potentially useful framework for England was promoted by the Department of Health in 2001. It remains available, although it is rarely referred to by government.[41]

Rights in care homes

All the rights described in this chapter apply equally in care homes whether residential, nursing or specialist, such as homes for people with dementia. So your right to see your GP or obtain free disability equipment or clothing such as a wheelchair or continence pads is unaffected by your residence in a care home. Similarly, if you or your relative needs a referral to an audiologist for a hearing aid or to a clinical psychologist to help with problems associated with dementia, ask your or their GP for one – just as you would if you or they were living at home. The fact that a nurse is required to be present at all times in a nursing home *(see Glossary)* should not affect your health rights.

The NHS: Rights and pledges

- The NHS Constitution sets out important health rights, but it is not well known.
- Entitlement to free healthcare includes equipment such as hearing aids and continence pads.
- Make sure a personal health budget will cover the costs of your healthcare.
- Choose your GP carefully, after a preliminary consultation.
- Appoint attorneys or named consultees to give or withhold medical consent if you should become incapable of doing so.
- Watch out for treatments and tests that you might want to refuse.
- Exercise your right to choice in treatment, GP and hospital.
- Expect NICE guidance to be followed for your ailments.
- Ask for your annual health check if you are 75 or over.
- Get your own copy of your patient records.