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### **Submission**

### **New Health Ombudsman**

#### **Submission re-health complaints and current health complaints authorities**

I commend the health Minister Honourable Lawrence Springborg in taking the important initiative in bringing about changes to the way health complaints will be addressed in Queensland,

The issues surrounding the way health complaints were previously addressed in Queensland by the HQCC and other health complaints bodies are long overdue.

Health complaints was to be a major part of health reform in Australia, this issue has fallen well short of those expectations that consumers were led to believe would happen, the same problems that existed in 2005 re-Dr Patel still exist for the consumer making a complaint in 2013.

Health reform only added to the confusion of how to make a complaint or what was expected when making a complaint by the consumer, this reform has led to many complaints bodies overlapping one another, APRHA has proven in other states particularly in Victoria to ignore consumers complaints in favour of doctors, and victims have basically been ignored or fobbed off, there has been no real accountability or responsibility taken by APRHA and many believe the reason being is that there are doctors investigating doctors, in other words it's a case of the devil investigating the devil where again consumers have been

fobbed off and negligent doctors rewarded allowed to continue to work without any accountability, which leads to an unsafe health system and no regard to patient safety in some cases.

I have been a long-time advocate for victims of medical negligent and adverse outcomes relating to medical procedures,

For a brief period in 2012 I was State manager for Victorian-based Australian Patients Association (APA) which operated out of the office of Brisbane-based lawyers Walsh Halligan Douglas.

In 2005 I represented the Fraser Coast health victims in dealing with HQCC many victims were bullied, fobbed off or called liars when complaints were made this was by a body that was supposed to represent openness and fairness for both the health professional and the consumer, yet it seemed the consumer was made to feel like they were being investigated, since then nothing much has changed for the victim.

Being part of Health Consumers Queensland Network it was not unusual to hear stories of similar magnitude. For the health system to change there is a greater need to be open and transparent, so that doctors and other Health Professionals who are continually making adverse errors are held accountable, properly monitored or supervised,

So must the Health Complaints body change to address these issues and be more than just a Monitoring and Reporting Authority as it stands today.

One of The biggest issue faced by consumers when making a complaint his lack of compassion and empathy by both health professionals and complaints body, both seem to produce a negative view on the consumer making a complaint going so far as to make the victim feel incompetent, mentally unstable,(it's in your head) or of lying.

While government spend millions of dollars covering up or Defending Negligent Medical procedures and Adverse outcomes for fear of Litigation, when in most cases of Medical Negligence all it would take is a few minutes of a health experts time to explain what went wrong, most consumers just want an explanation it's when they are ignored that they seek to sue,

This process of open disclosure has been used in the United States for many years and reduced litigation by up to 30%. My own experience in advocating for consumers support that process and has been the view of the many victims involved in adverse medical outcomes that they **“only wanted to know what went wrong”**

### **“Health Complaints and current Health Complaints Authorities”**

Health Quality and Complaints Commission (HQCC), Australian Health Practitioners Regulation Agency (APRHA), and the Medical Board of Australia, all have something to answer for when it comes to the inadequacies in dealing with health complaints in Queensland.

The current health complaints system in Queensland has for a long time been inadequate and incompetent in meeting the needs of consumers rights in making a complaint against health professionals i.e. hospitals, doctors etc.,

The new health complaints body should not only be consumer friendly and focused, with consumers having hands-on involvement in decision-making and part of the committee or network, but also Health Focused. Queensland does not need another **Toothless Tiger** when dealing with Complaints.

The implementation of strong complaints criteria is not only a benefit for the consumer but also benefits the healthcare profession.

Without a powerful complaints body a dominating closed culture which has existed in our health system will never change. To move to change old cultural habits and bring about a more open and transparent medical profession there needs to exist a strong and enforceable complaints model, with the power to enforce sanctions, compliance, and accountability, as well seek compensation on behalf on the victim. These measures are needed in today’s health environment to not only protect the consumer but to ensure that the duty of care owed to the public by health professionals is not a subject that should ever be questioned or up for debate. With every profession comes a certain degree risk, those risks can be minimised with accountability, transparency and a willingness to take extreme care when it comes to the health and treatment of another human being.

Too many times we hear in the media or consumers that **“we learn from our mistakes”** or **“we don’t want this to happen to anyone else”** that excuse is like a broken record considering in 2005 the commission of enquiry into Queensland Health regarding Dr Patel should have ensured that in 2013 medical mistakes would not be occurring at the rate they are today.

And with a strong complaints process hopefully the government can say **“we have learned from our mistakes”** and give the new complaints body the powers necessary to ensure we never have to repeat those words.

Patient’s rights need to be adequately addressed and protected when making a complaint that needs to be considered in structuring the new health ombudsman/health complaints body, consideration needs to be given in a number of areas particularly the position of vulnerability and trust that the patient placed in the health professional they are making a complaint about, whether it be a minor complaint regarding a question, or a more serious complaint regarding an adverse medical outcome, all of these experiences can be traumatic to any patient no matter how insignificant it may seem to the investigator or investigating officers when dealing with fragile consumers.

Adverse medical outcomes not only affect the victim but also the victim’s family and in some cases may have devastating long-lasting effects that are not considered at present by health complaints bodies or governments.

The days of doctors protecting their own need not be encouraged in our current climate otherwise it will just manifest more Dr Patel’s and push those whistle-blowers into further fear if they speak out they will be condemned, making a complaint against a health professional does not always have to be viewed as a negative but as a positive that can lead to not only a better health system but better health professionals who are not afraid to address their inadequacies or seek further training therefore the winner will always be the patient when we finally have an open and transparent health professionals who are not afraid of being reprimanded for speaking out.

In the setting up of a new health complaints authority I believe special attention should be given to **Patients’ Rights, Open Disclosure, Accountability, Responsibility, Transparency, Compensation, Counselling, Mediation, Rehabilitation, Corrective Procedure, Patient’s Medical History, Cultural,**

**Prematurely Closing of Complaint, Referring a Complaint, Prosecution of Health Professional, Perjury of Health Professional, Experience of Health Professional, Supervision of Health Professional, Co-operation of Health Professional, Hearing the Needs and Concerns of the Consumer, Closure for the patient.**

The new appointed health complaints authority would benefit with powers similar to a coroner or attorney general where they have the power for recommendations sanctions, prosecution or referrals to a higher authority so that a complaint can be investigated at a higher level particularly if a patient dies as a result of medical negligence or medical procedure. This power would override government intervention.

**The Biggest issue I see with any Complaints Authority is that they have not been given the Power to Prosecute in Australia, so until that happens Changes that need to be Made in Health-care will continue to be ignored.**

**The Charter of Healthcare Rights changed to make it a law in Queensland under a "Bill of Rights" similar to the United States ensuring patients' rights are upheld. (File Attached)**

**Mediation and Compensation: -The new health complaints body has the power to mediate for compensation on behalf of a health victim, the power to initiate mediation between patient and health professional, the power to ensure health professionals cooperate and present themselves for questioning in relation to a complaint and refusal to do so could lead to either suspension, reprimand or a fine.**

**Closing a complaint and corrective procedure:-complaints are not to be signed off prematurely. Currently health complaints investigators are not thorough enough the investigators leave too many questions unanswered too many complaints unresolved, too many patients fobbed off, as well as complaints being closed against the wishes of the victim.**

**Open Disclosure, Responsibility and Accountability:**

Part of recommendations under health reform was the implementation of **“Open Disclosure”** which I don’t believe has been enforced or encouraged, not by health professionals, governments or complaints bodies.

To ensure the complainant receives the full benefit of an investigation/review open disclosure needs to be made mandatory and implemented into investigating procedures.

This procedure (**open disclosure**) has major benefits not only to the consumer/victim but also to governments and health care providers.

- 1. Closure and healing for the victim.**
- 2. Responsibility and accountability for the healthcare provider.**
- 3. Helps facilitate a speedy resolution to finalise a complaint.**
- 4. Reduces litigation**

**Full disclosure by the health professional/hospital involved to be part of the investigation process, this process has proved successful in the United States reducing litigation by 30%.**

Consumer representatives to be part of the complaints investigation process also a consumer Representative/Advocate with the experience in the complaints process are part of, and offered to the victim making the complaint to act in the patient’s best interests and not the best interest of the health professional the government or the complaints body.

**Transparency:-** under the current health complaints controlled by HQCC the system provides the status of a monitoring and information service which has no real effect on changing the bad cultural scene in Queensland Health, has no real benefit to a complaint or changing the health system in Queensland. HQCC has no power to ensure transparency, open disclosure or accountability, patients/consumers need to be part of and have an input into questions presented on their behalf during an investigation against a healthcare provider.

The focus also needs to hold **Accountable Hospital Managers/ Boards** for any failure to make available a patient's medical records in an appropriate time frame. As well as make available at the request of the new health complaints body any health professional for questioning that is related to any complaint or investigation.

**The New health complaints body** make it mandatory to conduct a face-to-face open disclosure mediation process as part of its investigation to ensure accountability transparency and part of closure for the victim or their family.

**Has power to refer a complaint:-**

Referring all non-compliance names to the health Minister and medical board will further insurer investigations or sanctions.

Refer continual complaint findings of a healthcare provider to the health Minister and medical board for further investigation or sanction.

**The new health complaints body** have the power to recommend a healthcare provider undergo further training or voice training as a condition of findings and further training assessments be monitored not only by the medical board but also the health Minister.

While investigating a complaint further questions need to be asked of either the healthcare provider or victim.

Q. Were or has patient being given a copy of the charter of healthcare rights.

1. before admission
2. During consultation
3. When admitted
4. If not ,why not?
5. Did they understand the charter of healthcare rights?

In summing up when dealing with a complaint it **Must** be measured the same way as we expect health professionals to deal with their patients, with Compassion, Accountability, Transparency, Full Disclosure, and the Duty of Care owed to the victim.

**I am available to present as a witness if requested/required by the Committee**

**Laurie Brock**



**Founder :- mvas**

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## THE PATIENT'S BILL OF RIGHTS

(as established by the American Hospital Association)

The hospital shall establish written policies regarding the rights of patients upon admission for treatment as an inpatient, outpatient, or emergency room patient, and shall develop procedures implementing such policies. These rights, policies, and procedures shall afford patients the right to:

1. receive emergency medical care, as indicated by the patient's medical condition, upon arrival at a hospital for the purpose of obtaining emergency medical treatment;
2. considerate and respectful care;
3. obtain the name of the physician assigned the responsibility for coordinating his or her care and the right to consult with a private physician and/or a specialist for the type of care being rendered, provided such physician has been accorded hospital staff privileges;
4. the name and function of any person providing treatment to the patient;
5. obtain from his or her physician complete current information concerning diagnosis, treatment and prognosis in terms the patient can reasonably be expected to understand;
6. receive from his or her physician information necessary to give informed consent prior to the start of any nonemergency procedure or treatment or both. An informed consent shall include, as a minimum, the specific procedure or treatment or both, the reasonably foreseeable risks involved, and alternatives for care or treatment, if any, as a reasonable medical practitioner under similar circumstances would disclose;
7. refuse treatment to the extent permitted by law, and to be informed of the medical consequences of his or her action.
8. privacy to the extent consistent with providing adequate medical care to the patient. This shall not preclude discreet discussion of a patient's case or examination of a patient by appropriate health-care personnel;
9. privacy and confidentiality of all records pertaining to the patient's treatment, except as otherwise provided by law or third-party payment contract;
10. a response by the hospital in a reasonable manner, to the patient's request for services customarily rendered by the hospital consistent with the patient's treatment;
11. be informed by his or her physician, or designee of the physician, of the patient's continuing health-care requirement following discharge, and that before transferring a patient to another facility the hospital first informs the patient of the need for and alternatives to such a transfer;
12. the identity, upon request, of other health care and educational institutions that the hospital has authorized to participate in the patient's treatment;
13. refuse to participate in research and that human experimentation affecting care or treatment shall be performed only with the patient's informed effective consent;
14. examine and receive an explanation of his or her bill, regardless of source of payment;
15. know the hospital rules and regulations that apply to his or her conduct as a patient.
16. treatment without discrimination as to race, color, religion, sex, national origin or source of payment, except for fiscal capability thereof;
17. designate any private accommodation to which admitted as a nonsmoking area. In the event that private accommodations are not available, a patient shall have a right to be admitted to accommodations which have been designated by the governing authority as a nonsmoking area. It shall be the duty of the governing authority of the hospital to afford priority to the rights of nonsmokers in all semiprivate, ward, and pediatric common patient areas; and
18. voice grievances and recommend changes in policies and services to the facility's staff, the governing authority and the state department of health without fear of reprisal.

A copy of the provisions of this section shall be made available to each patient or patient's representatives upon admission for treatment as an inpatient, outpatient, and/or emergency room patient, and posted in conspicuous places within the hospital.

omitted.) Nevertheless, a patient is within rights in asking to see the chart. Much has been made of the possibility that a patient may not be able to cope with the information found there. In fact, however, hospital charts—written by doctors and nurses in

medical shorthand as a record for other health professionals—are seldom helpful to patients who are curious about their conditions.

While hospitals acknowledge the patient's right to privacy concerning program and records, in prac-

## Acknowledgments

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OVER THE LAST THREE YEARS, scores of people have been involved in creating *The Columbia University College of Physicians and Surgeons Complete Home Medical Guide*. While it is impossible to cite all of the many dedicated physicians, consultants, writers, editors, illustrators, and others who have contributed so much to this book, there are some whose dedication and efforts deserve special mention.

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safer than early antibiotics such as chloramphenicol (which has been limited to use in special situations) and effectively combat a much broader spectrum of bacteria.

We are just beginning to develop treatments for viral diseases, but have succeeded in decreasing many viral illnesses dramatically through immunization. Measles, mumps, and rubella (German measles), once almost universal among children and, in the case of rubella, responsible for numerous birth defects, are becoming uncommon. One viral disease, smallpox, which was a leading cause of death internationally, has actually been eradicated from the face of the earth. Polio, at least in industrialized nations, may soon face a similar fate.

Thousands of people with inflammatory diseases such as arthritis have benefited from the development of steroids (such as cortisone) and then nonsteroidal anti-inflammatory drugs. In the case of one specific kind of arthritis—gout—a precise understanding of body chemistry has yielded a drug (allopurinol) which specifically counteracts the responsible genetic defect.

Another set of biomedical discoveries led recently to a medication (cimetidine) which acts on the surface of acid-producing cells in the stomach to control peptic ulcer disease.

The intensive care now provided routinely after heart attacks includes, when needed, electronic monitoring of cardiac function, drugs to correct faulty rhythms and to control blood pressure, potent diuretics to rid the body of extra fluids, and the insertion of artificial pacemakers.

The field of psychiatry has been revolutionized by antipsychotic, anti-anxiety (tranquillizing), and antidepressive drugs, so that patients once hospitalized for years are now back home within weeks, and the total number of American psychiatric hospital beds is a fraction of the number in 1950.

Maternal and infant complications in obstetrics have declined with better prenatal care, including the careful control of high blood pressure and diabetes during pregnancy, fetal monitoring to detect early distress, and safer cesarean sections. Full un-

derstanding of Rh blood type incompatibilities between mother and fetus has led to a drug that can prevent this potentially fatal disorder.

Much of surgery has been transformed by a basic understanding of the healing process, the development of better anesthetics and techniques for their administration, intravenous feeding, and modern blood banking. The invention of pump-oxygenator "bypass" equipment has permitted surgeons to stop a patient's heart, open it, and repair it as never before. Microsurgical techniques now make it possible to reattach severed limbs, to repair the tiny bones of the middle ear, and to bypass clogged arteries in the heart or limbs with natural or synthetic substitutes.

In the most impressive advance of recent decades, organ transplantation—most successful so far for kidneys—has been made possible by combined efforts in surgery and the medical fields of dialysis and immunology.

The biomedical revolution outlined above has had a great impact on the health of Americans and citizens of other industrialized nations. Some of its benefits are reflected in improvements in traditional measures of population health: decreased infant mortality, a modest decrease in death rates for adults and a slight increase in adult life expectancy, and moderate decreases in the prevalence of certain diseases. But much of the benefit remains uncounted. Even the most successful new drug for arthritis will have no impact at all on death rates or life expectancy. Nor will the prevalence of arthritis be affected. What will change is the amount of pain and the degree of function experienced by arthritis sufferers, and these are very difficult to measure. I cannot agree with some of modern medicine's critics who totally discount the value of diagnostic and therapeutic progress.

At the same time, it must be admitted that the rapid advances in postwar medicine have been flawed in several significant ways, so that their full potential has been blunted by negative impacts. Uncritical acclaim for technological progress would be just as nearsighted as total rejection.

### CURING VERSUS CARING

HIPPOCRATES PRACTICED MEDICINE 400 years before the birth of Christ. In the 2,300 years between his time and the start of this century, there was little that physicians could do technologically to help their patients. Why, then, were doctors respected and sought after during these 23 centuries? Primar-

ily because they exercised interpersonal skills valued by their patients. They knew which disorders were usually minor and provided reassurance and hope to patients who suffered from them. They knew which disorders were often long-lasting, disabling, or fatal, and—to such patients and their families—

they provided understanding and support. They helped their patients to cope, to suffer and endure, to grieve. They listened.

Now that physicians *do* have the tools to cure many patients, the interpersonal skills are almost entirely ignored in medical education and underutilized by many in practice. Compassionate physicians still exist but they are rarely seen by medical students, whose only role models are biomedical researchers and subspecialty clinicians in referral practice.

The unbalanced emphasis on technology and the inattention to interpersonal communication skills are due in part to the massive funding of the former in medical schools and by insurance companies. Private insurance, Medicaid, and Medicare will all pay handsomely for operations, x-rays, and other technological interventions which may require relatively little time on the part of physicians. They pay less—and sometimes do not pay at all—for time spent counseling and listening.

Factors that go beyond the health-care system also play a role. In our society as a whole, a high level of prestige is attached to fast, dramatic actions based on technological solutions, as opposed to prolonged, gradual progress based on relationships. In such a society, it is not surprising that doctors want to quickly diagnose and cure, and are less enthusiastic about patient problems that require gradual education and counseling.

Many patients reinforce this unbalanced emphasis. Critics of the current system have objected to the "medicalization" of society, in which the public expects a pill to "cure" every ache, anxiety, and stress. Ivan Illich points out that this trend has made us less able to cope, to resolve our own problems, and to bear suffering when no pill will work.

A frequent way of expressing these concerns is to state that we emphasize the *science* of medicine and ignore the *art*, an equally essential component.

To some extent this is a valid analysis. On the other hand, in the long run it is dangerous to label—and dismiss—interpersonal skills as an "art." In fact there are social sciences which deal with this area rather effectively.

A doctor who successfully treats your heart attack is a good doctor. A doctor who helps you to avoid having the heart attack in the first place is a better doctor. At the present time, we say that this superior physician knows the "art" of medicine. He or she was never taught it in medical school, but somehow "picked it up" or had an "innate ability" all along.

This is an unfortunate attitude. Physicians can learn more effective ways to educate and motivate patients concerning risk factors such as smoking, exercise, and diet so that they are less likely to have heart attacks. There is a great deal of real science required. It just does not happen to be "bench science" involving test tubes.

In the prevention of disease and in the management, especially, of chronic disease, the physician can be an important part of care. And it is possible to learn, "scientifically," to do this well. On a societal level, what is needed is more research in the sociomedical as well as the biomedical sciences, so that interpersonal skills in the patient-physician relationship can be further heightened. In the meanwhile, medical students need a broader range of role models which will only come about through reforms in the funding of medical schools. Payments for care must also be revised so that practicing physicians have incentives to spend time with patients.

On a personal level, patients must seek out those physicians who will listen and who are willing to develop therapeutic relationships. Such doctors do exist, but are too often bypassed by patients who are overly impressed by academic, research-based credentials.

## THE CHANGING STRUCTURE OF HEALTH CARE

IN THE 1940s, the vast majority of American medical care was provided by general practitioners in non-hospital-based solo offices. Their patients paid them directly. Forty years later, the majority of our doctors are specialists, sometimes practicing in groups or clinics and more often in formal or informal partnerships. Their offices are often within or immediately adjacent to hospitals, and their bills go increasingly to insurance companies or governmental agencies, not to their patients.

Two of these changes have fostered the decline in the patient-physician communication that we have discussed. "Third-party payments"—payments by anyone other than the patient—now account for over 40 percent of all health-care reimbursements. To the extent that insurance frees patients from financial burdens and removes barriers to needed care, this is a blessing. Unfortunately, physicians who need not worry about their patients' ability to pay are less likely to give careful consid-

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tal. The surgical team—the surgeon, the anesthesiologist, the operating room nurse, and their assistants—is technologically oriented and works with speed. Patients will be closely observed but should not expect much “tender loving care.” With a general anesthetic, the patient will be completely unaware of what is going on, even with a spinal or local anesthetic, the patient will be less alert because of the preoperative sedation.

After any operation that requires a general anesthetic, patients are taken from the operating room to a special recovery room. Here, “vital signs” (pulse, temperature, respiration, and blood pressure) will be checked every few minutes for an hour or so, to ensure that the patient is recovering satisfactorily from the anesthetic. In addition, a nurse will call the patient’s name and ask him or her to respond, testing the extent to which the anesthesia has “worn off.”

**Recovery.** The patient will be taken back to his or her room once the vital signs have stabilized and the patient has begun to emerge from the anesthesia. Pain at the site of the operation is to be expected and there may also be nausea and vomiting. Medications are available for the relief of these postoperative symptoms, and patients should make their needs known.

One aftereffect of general anesthesia is an increase in lung secretions and a consequent risk of pneumonia. Turning in bed and breathing deeply will help the patient mobilize these secretions, coughing brings them up. Turning, coughing, and deep breathing (TCDB in nurses’ shorthand) may be painful but are essential to keep the lungs clear. Early ambulation has much the same effect and the additional benefit of preventing muscle deterioration, which can begin after only a few days’ immobility.

A spinal anesthetic alters the pressure of fluids within the spinal column. It is important for the patient to follow postoperative instructions carefully so as to avoid the headaches that may accompany pressure changes as the spinal fluid readjusts. Usually it is recommended that a patient who has had a spinal anesthetic lie completely flat (on the back, and without a pillow) for 12 hours or more.

If the patient has had an abdominal operation, a nasogastric tube (running from the stomach up through the esophagus and exiting at the nose) will have been put in place at the end of the operation, to remain for several days. This tube carries out stomach gases that might otherwise accumulate and cause great discomfort. Even so, the patient is likely to have some gas pain on the third day after the operation when the gastric juices become active again.

Depending on the operation, the patient may have other tubes that drain excess fluid from the site of the surgery. There may also be an intravenous tube that delivers fluid and possibly nutrients to a vein in the arm. It may lessen the patient’s anxiety to know, before the operation, what measures of this kind to expect.

### Patients’ Rights

In 1973, following years of bad publicity and pressure from consumer groups, the American Hospital Association formalized a list of the rights of hospitalized patients. This list can be found posted in hospital corridors (in accredited hospitals, it is mandatory to post it) and it is often printed in patient information handbooks. (See the box on page 29.)

Points 5, 6, and 7 concern the concept of “informed consent,” which cannot be separated from that of “necessary information.” Together, these rights mean that:

- A patient has the right to understand what is medically the matter, and what the doctor intends to do. This explanation does not have to be highly detailed or technical, the patient, however, should understand in a general way what is involved in his condition and in the procedures planned.
- A patient should know what the potential risks of the proposed treatment or procedure are. The doctor is required to provide this information. (In addition, there are statistical probability tables on the frequency of death and serious complications for almost every disease treated in a hospital; the data for the local hospital are usually available, as well as regional and national figures.)
- A patient also has the right to know what measures other than the one proposed by the doctor are available, and what their risks are. (It should be noted that a surgeon’s list of alternative measures may differ from an internist’s.) He or she has the further right to know the probable outcome if only the most conservative treatment—“do nothing” procedures—is undertaken.
- A patient should understand that he or she is not being coerced into complying with the doctor’s plans, is choosing freely, and can reject treatment if he or she changes his or her mind.
- A patient should be aware that any treatment of body or mind without voluntary, fully informed consent is a wrongful act.

Points 8 and 9 concern privacy of information. A patient’s chart is not his or her property. (It is, in fact, a legal document, the property of the hospital. Only that information that would be salient in the courtroom must be included; much is therefore

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3. obtain the name of the physician assigned the responsibility for coordinating his or her care and the right to consult with a private physician and/or a specialist for the type of care being rendered, provided such physician has been accorded hospital staff privileges;
4. the name and function of any person providing treatment to the patient;
5. obtain from his or her physician complete current information concerning diagnosis, treatment and prognosis in terms the patient can reasonably be expected to understand;
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11. be informed by his or her physician, or designee of the physician, of the patient's continuing health-care requirement following discharge, and that before transferring a patient to another facility the hospital first informs the patient of the need for and alternatives to such a transfer;
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14. examine and receive an explanation of his or her bill, regardless of source of payment;
15. know the hospital rules and regulations that apply to his or her conduct as a patient.
16. treatment without discrimination as to race, color, religion, sex, national origin or source of payment, except for fiscal capability thereof;
17. designate any private accommodation to which admitted as a nonsmoking area. In the event that private accommodations are not available, a patient shall have a right to be admitted to accommodations which have been designated by the governing authority as a nonsmoking area. It shall be the duty of the governing authority of the hospital to afford priority to the rights of nonsmokers in all semiprivate, ward, and pediatric common patient areas; and
18. voice grievances and recommend changes in policies and services to the facility's staff, the governing authority and the state department of health without fear of reprisal.

A copy of the provisions of this section shall be made available to each patient or patient's representatives upon admission for treatment as an inpatient, outpatient, and/or emergency room patient, and posted in conspicuous places within the hospital.

omitted.) Nevertheless, a patient is within rights in asking to see the chart. Much has been made of the possibility that a patient may not be able to cope with the information found there. In fact, however, hospital charts—written by doctors and nurses in

medical shorthand as a record for other health professionals—are seldom helpful to patients who are curious about their conditions.

While hospitals acknowledge the patient's right to privacy concerning program and records, in prac-

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tice this is difficult to achieve. Details of the patient's condition will inevitably be known, not only to doctors, nurses, and aides, but also to technicians in many different areas—and to the billing department.

The Patient's Bill of Rights was adopted by the American Hospital Association in an attempt to improve relations between patients and hospitals. It has been promoted by many as a legal document, or as a document that has the potential of being legally binding. However, enforcement of any of these rights would be difficult. They deal to a large extent with intangible factors—consideration, respect, confidentiality, reasonableness—that affect the relationship between patients and those who treat them. Nevertheless, patients who feel that their rights have been violated should *always* raise the issue with their doctors and the hospital staff (see Remedying Deficient Hospital Care, page 32).

#### The Patient's Role in the Hospital

Patients who understand the goals of their medical programs, and cooperate actively with those who are treating them, can make a great difference in the speed of their recovery. Their rights as patients include the right to a full disclosure, in lay language, about their condition and the procedures that are planned (see The Patient's Bill of Rights, page 29). It is their responsibility to exercise this right by asking questions about anything that is not clear to them. (It may be helpful for them to have written notes about questions to ask and also to make notes on the answers.) A patient has a right to read his or her own medical record.

A patient should ask the doctor in advance for details about recovery—whether there will be discomfort or pain and for how long, when is a reasonable time to expect discharge, and how long activities may be limited afterward. Knowing what to expect lessens anxiety and speeds recovery.

Discharge of the patient as soon as it is medically advisable, with continued convalescence at home, in an extended-care facility, or in a nursing home is in everyone's best interest, and the patient should be willing to leave as soon as the doctor gives an okay. A hospital stay prolonged unnecessarily may deprive another patient of a needed bed. In addition, inefficient use of hospital facilities is an important cause of the spiraling cost of medical care.

Although the patient may be ready to do "anything to get well," he or she should be alert to the fact that the "anything" may be merely a fossilized hospital routine. Questions about routines that seem inappropriate may earn him or her the label of a "difficult" patient, that is, an assertive rather than

a passive one. But the staff's expectation of unquestioning compliance on the part of patients is not legitimate, and a healthy assertiveness is an important step toward recovery.

#### In Case of Death

If the patient's illness is serious, and there is a possibility of death while in the hospital, there are certain things that should be taken into consideration. The patient may, for example, want to consider donating tissues or body organs (the corneas of the eye, skin, bone, pancreas, or kidneys, among others), or the whole body. In many states, patients 18 or older can authorize that all or any parts of their body be used for specified purposes after death, under the Anatomical Gift Act. Alternatively, the patient can let the immediate family know of his wishes; they can then give the necessary permission. Those wishing to donate their bodies to medical education (dissection of the human body is an essential part of students' training) should contact the department of anatomy, or the dean's office, at any medical school. Usually, bodies used for these purposes are later cremated.

If a member of the family dies while in the hospital, the question of an autopsy may arise. In some hospitals, autopsy is mandatory under certain circumstances—for example, a sudden or unexpected death, or a death during surgery. Usually, however, an autopsy is done at the hospital's request and with the family's permission. (Permission is requested in priority order, from the surviving spouse to more remote relatives.)

For many people, giving permission for an autopsy is not an easy decision to make. However, there are at least two good reasons for doing so. First, since several diseases are known to have hereditary risk factors, families who know the cause of death of one of their members may be able to take steps to avoid succumbing to the same disease.

Although the cause of death may seem to be clear, this is not always the case. There is a reported 40 to 50 percent difference between diagnoses made before death and the findings at autopsy. Second, an autopsy may contribute indirectly to the health of future generations of the country as a whole. Mortality figures often influence decisions as to the allocation of money for research. For example, the research focus on heart disease is in large part due to the fact that mortality figures have established this as the leading cause of death in this country. It is therefore of long-range importance that mortality figures are based to the greatest degree possible on fact rather than on guesswork.

Autopsies are performed by pathologists, who