

## 2 TAKING CONTROL OF YOUR HEALTH CARE DECISIONS

### 2.1 Introduction

As you get older, you are more likely to have to make major decisions about your health, including regular and ongoing treatment, emergency procedures, and long term health care. This chapter is divided into two main sections, the first regarding the making of decisions relating to medical treatments and the second relating to the Australian healthcare system.



### 2.2 Consent to medical treatment

You can validly consent to medical treatment only when your consent is given freely. For example, if you consent merely because you believe you will otherwise be refused further treatment then your consent has not been validly given. In addition, you should receive accurate and appropriate information about your condition, treatments and proposed procedures.

To ensure that your consent is valid, you should be provided with as much information as possible. Amongst other things, you should be told and understand:

- (a) your condition, or illness, including its severity or the result of any tests which you undergo;
- (b) the diagnosis of your condition and the accuracy of the assessment;
- (c) the various treatments which are available and the relative advantages and disadvantages of each, the risks associated with these, including possible side effects and likely outcomes;
- (d) what will be done, how long it will take and expected recovery time;
- (e) the financial cost of any procedures or treatment; and
- (f) the qualification and experience of doctors and others who may be treating you.

Consent must be given for the particular procedure or treatment. If you consent to a particular course of action, the doctor (unless special circumstances arise) cannot carry out a different treatment.

In emergencies, where treatment is urgent and life saving, consent is not required to prevent serious damage to a patient's health or to prevent the patient from suffering significant pain, and the consent cannot be obtained, for example if you are unconscious. In these cases doctors and other health workers are under a duty to act in your best interests. Also, consent is not required if the treatment has been authorised by the Guardianship Tribunal or with a Supreme Court order. Consent is also not required where treatment is authorised by legislation, for example, such as compulsory blood testing on traffic accident victims and certain treatments under the *Mental Health Act 1990*.

### 2.3 Withholding consent

Generally, a fully competent patient is capable of refusing treatment or medical procedures. You, as a patient, have a right to self-determination and personal autonomy. However, this is contingent upon whether you have capacity, which is explained below.

However, where a guardian is appointed for a patient, the failure to consent may be overridden by the Guardianship Tribunal or a Court.

## 2.4 What happens if you are unable to consent?

In most cases, a doctor can only give you medical treatment if you have consented to that treatment (except in emergencies, as set out above). If you lack capacity, you cannot give consent to that treatment, unless you have specified your wishes about the treatment before losing capacity.

## 2.5 Capacity

Decisions about your health care, whether it be immediate treatment, or long term health care, are only valid if you have capacity when you make the decision.

To 'have capacity', you must be capable of understanding the nature of the decision you are making and the effects that that decision will have on you and on others.

If you have capacity, you are described as being 'capable'.

## 2.6 How is capacity measured?

There are no numeric measures or tests which can be done to determine if you have capacity. Capacity is not determined by whether you can perform a certain task, or by whether your decision is seen as wise by the people around you.

Capacity is measured by your ability to understand the nature and consequences of a specific decision. For example, you may have capacity to make a decision about whether to be treated for a particular health problem, because you can understand what is wrong with you, what the treatment will involve, and what the long term consequences of the treatment will be, but at the same time not have capacity to manage your financial affairs, because you are not capable of understanding the extent and nature of your finances, and the consequences of the decisions you are making about your finances.

People with mild intellectual disabilities may still be capable. It is also possible that you may lose capacity temporarily, for example if you suffer from an illness, but later recover from it. People in the early stages of dementia may lose capacity on a temporary basis.

Your capacity to make a decision is assessed at the time that you need to make that decision. If you are assessed as not being capable, this does not necessarily mean that you will never have capacity again.

## 2.7 What happens if a person doesn't have capacity?

If you don't have capacity and you have not specified how you want to be treated before losing capacity, someone else will make the decision about whether you should receive medical treatment and, if so, what sort of treatment that should be.

The *Guardianship Act 1987* sets out a list of people who will make that decision for you if you lack capacity. The decision will be made by a "person responsible" who will be either:

- (a) a guardian or enduring guardian (see below for definitions of guardians and enduring guardians); or, if there is no guardian or enduring guardian,
- (b) the most recent spouse, de facto spouse or same sex partner with whom you have a close and continuing relationship; or, if there is no spouse, de facto spouse or same sex partner,
- (c) an unpaid carer who is now providing support to the patient or provided support before the patient entered residential care; or, if there is no carer,
- (d) a relative or friend who has a close personal relationship with the patient.

## 2.8 Guardians

There are three types of guardians in NSW:

- (a) enduring guardians – people appointed by the person with a disability, prior to that person's loss of capacity, to be his or her guardian;
- (b) private guardians – close family members and/or friends who are appointed by the Guardianship Tribunal to be the guardian of a person with a disability; and
- (c) public guardians – the NSW Public Guardian is a public official who can be appointed by the Guardianship Tribunal to be guardian of a person with a disability when there is no other person suitable to be a guardian.

When appointing a public or private guardian the Guardianship Tribunal must be satisfied that the proposed guardian's personality is generally compatible with the person under guardianship, that there is no undue conflict between the interests, and that the guardian is willing and able to exercise his or her functions.

If there is no one falling within any of these categories, the Guardianship Tribunal may act as a substitute decision maker.

The decision maker gives consent if minor medical or dental treatment is required. If the decision maker is not available, the doctor or dentist can proceed with minor treatment without consent if they can see from the patient's record that the treatment is necessary to promote the patient's health and well being and that the patient is not objecting to the treatment.

For major medical treatment, only the decision maker or the Guardianship Tribunal can give consent.

Consent cannot be given for treatments that are administered for the benefit of health carers, or health professionals. For example, an aged care facility that is short of staff cannot ask a decision maker to consent to sedate residents to make it easier to care for them.

For persons having a public guardian, it is now possible to seek review of a decision made by the public guardian at the Administrative Decisions Tribunal.

People who have been appointed as a guardian by the Guardianship Tribunal or a Court can receive support and information from the Private Guardian Support Unit, the full contact details are set out in Chapter 14.

## 2.9 How can I retain control over my health care decisions if I lose capacity?

The important thing is to plan ahead.

As discussed above, every person has the right to refuse or accept medical treatment, but the difficulty arises when you wish to ensure that you receive the treatment that you desire, when you are not in a position to make your preferences and desires clear.

You need to make clear your wishes about your future health care while you still have capacity. Some informal ways of doing this are by making your wishes known to friends, relatives and your doctor, and by writing your wishes down.

There are also some formal legal steps that you can take to ensure that your wishes are respected. In this respect, you may consider the following possibilities:

- (a) appointing an enduring guardian; and/or
- (b) writing an advance health care directive - "living wills".

## 2.10 Enduring guardians

An enduring guardian is someone that you appoint to make personal and lifestyle decisions and/or decisions about medical treatment on your behalf, if you are unable to make those decisions yourself. Appointing an enduring guardian determines who can make a decision on your behalf, but it does not deal with the content of those decisions. You may choose to rely on your enduring guardian's ability to make decisions and have confidence that they will act in your best interests. Alternatively, you may prefer to write down your wishes in the form of an advance health care directive, which is discussed further below.

The appointment of an enduring guardian must be in writing and in an approved form. Both you and your appointed enduring guardian must sign the document in front of your solicitor, barrister or a clerk of a local court. The appointment will only take effect when you no longer have the capacity to make decisions and are incapable of understanding the general nature and effect of proposed treatment and incapable of indicating your consent or opposition to the proposed treatment. You may appoint more than one enduring guardian to act on your behalf, or different enduring guardians with separate functions. Your enduring guardian must be over 18 years of age and not directly or indirectly involved in any aspect of your medical treatment.

An enduring guardian appointed to consent to medical and dental treatment can only act under Part 5 of the *Guardianship Act*, which authorises them to consent to major and minor treatments that will promote and maintain the health and wellbeing of the person who has appointed them. An enduring guardian can consent to a medical or surgical procedure, operation, examination and any prophylactic, palliative or rehabilitative care customarily carried out by a medical practitioner. The authority to consent depends on the specific type of treatment. In particular, an enduring guardian cannot commit on your behalf for special treatment, which includes any new treatment that has not yet gained the support of a substantial number of medical practitioners or dentists specialising in that area.

The appointment should detail the functions the enduring guardian is to exercise, and any conditions or limitations you desire. An enduring guardian does not have the authority to override your objections. You can revoke the appointment in writing, but only while you have the capacity to understand your decisions. Any revocation must be witnessed by your solicitor, barrister or a clerk of the local court and be given to the person previously appointed as your enduring guardian.

An enduring guardianship appointment can be reviewed by the Guardianship Tribunal or the Supreme Court, which can suspend, confirm, revoke or vary the appointment.

## 2.11 Advance Health Care Directives or "Living Wills"

An advance health care directive or "living will" is a written statement that contains information about the medical treatment you desire. It comes into effect only when you are no longer able to make your own decisions. In NSW, advance health care directives are not supported by legislation (that is, they are not legally binding), unless they are part of the appointment of an enduring guardian. However, if a potential decision maker, such as a health care worker or guardian of the Guardianship Tribunal, is aware of the existence of your advance health care directive, it is likely to be influential when decisions about your health care are made. An advance health care directive should be kept up to date and consistent with anything you have said to the decision maker previously.

As an advance health care directive has no set format, you may wish to consult a solicitor about preparing one. (Best practice guidelines are available from NSW Health at [www.health.nsw.gov.au](http://www.health.nsw.gov.au).) You should provide copies to your doctor, health care worker, friends and family as well as discussing the contents with them.

If you do nothing about planning, as discussed above, the Guardianship Act will apply to you by identifying persons who are best able to make decisions on your behalf.

## 2.12 Euthanasia

Euthanasia is the active and deliberate intervention by a second party to end life, with the express wish of the first party. This is distinct from discontinuing treatment or failing to consent to the commencement of treatment at the patient's request. Euthanasia is currently illegal in all states and territories in Australia.

## 2.13 No CPR orders

A "No Cardiopulmonary Resuscitation" (No CPR) order is an instruction that no attempt be made to resuscitate a person if heart failure occurs in the future. It is not a form of euthanasia. It is usually used by terminally ill or infirm patients.

## 2.14 The Australian health care system

There are two health insurance schemes currently operating in Australia - the Medicare scheme and private health insurance.

## 2.15 Private Patient versus Public Patient

Regardless of whether or not you have private health insurance, every patient has the right to elect to be treated either as a private patient or as a public patient. As a private patient, you will be billed for accommodation (in any hospital) and medical services, but will have your choice of doctor. Private patients will also be charged fees by the treating doctors. Medicare will cover 85% of the schedule fee for services and procedures provided (but makes no contribution towards accommodation, theatre costs etc). Private health insurance, depending on the level of cover, will pay for some of the remaining costs.

As a public patient, you will not be billed for care, treatment or after-care, but you will only be treated by the doctor on duty at the time.

So, your decision to take out private health insurance will depend on whether you prefer to be treated as a private patient, and/or if you need medical services which are not covered by Medicare. However, you should be mindful, before taking out private health cover, that medical services which are not covered by Medicare may not be covered by private insurance. You should check with the private health insurer if you are unsure what services they cover.

## 2.16 Who is covered under the Medicare scheme?

Medicare was introduced in 1984 to provide basic health insurance for hospital and medical care for all Australian residents. It provides free treatment as a public patient in a public hospital, and a rebate on fees paid to general practitioners, specialists and optometrists.

All Australian residents, once registered with Medicare, are covered under the scheme provided they either:

- (a) hold Australian citizenship;
- (b) hold permanent resident status;
- (c) hold New Zealand citizenship; or
- (d) have applied for a permanent residency (restrictions apply to persons who have applied for a parent visa and other requirements are applicable).

Visitors from Finland, Italy, Malta, the Netherlands, New Zealand, Sweden and the United Kingdom can also access Medicare under reciprocal arrangements between Australia and their home governments, although this is usually limited to emergency medical treatment only.

## **2.17 How much does medical assistance cost under the Medicare scheme and how does 'bulk billing' work?**

The government has prescribed a recommended fee ("the Schedule fee") for all medical services under the Medicare scheme. When a health professional 'bulk bills', this means that the practitioner is billing the government directly and you will not have to pay anything. While they are not legally required to, most practitioners will bulk bill specific classes of patients, such as pensioners and health care cardholders. If your local doctor does not you should look around for one that does.

Where a health professional invoices you for services, you can claim these costs from Medicare (either in the form of a reimbursement if you have paid the invoice, or a cheque made out to the health professional if you have not paid). Medicare pays 85% of the Schedule fee or the Schedule fee less \$52.50, whichever is the greater for outpatient services or, 75% of the Schedule fee for inpatient services. If the health professional charges more than the Schedule fee (which they frequently do) you will have to pay the 'gap amount' yourself. Once your gap payments per year total \$280.30, you are eligible for the Safety Net. (However, the Safety Net total only comprises the gap between what Medicare pays and the Schedule fee. If your medical practitioner charges more than the Schedule fee, this will not count towards your Safety Net total).

## **2.18 What is the Medicare Safety Net?**

The Medicare Safety Net operates once your gap payments have reached a certain level in a year. Medicare can keep a tally of your gap payments if you send them your receipts.

From that time on, Medicare benefits will increase from 85% of the Schedule fee to 100% of the Schedule fee for any further out-of-hospital services that year.

## **2.19 How do I register for the Safety Net?**

As an individual you do not need to register for the Safety Net. Provided Medicare has all of your receipts, higher benefits will become available as soon as you reach the Safety Net.

If you claim through Medicare as a family or a couple, you will need to complete a Safety Net registration form available from Medicare.

## **2.20 What is the Medicare levy surcharge?**

Although there is no direct charge to use the Medicare scheme, all taxpayers contribute via the Medicare levy in their annual tax return.

If you are single and earn over \$50,000, (or \$100,000 for couples/families) and do not have private health insurance, you will pay an additional 1% on top of the Medicare levy as part of your annual income tax return.

However, you will not be liable for the surcharge if your income does not exceed certain threshold for Medicare surcharge purposes. For the income year 2004/2005, the threshold for individuals is \$15,902 and for a family is \$26,834. Higher thresholds may apply to senior, pensioner and family with dependant children.

See Section 4.32 for more information on the Medicare levy.

## **2.21 What benefits does Medicare cover?**

Medicare covers the cost of:

- (a) consultation fees of doctors, including specialists;
- (b) tests and examinations needed to treat illness, including x-rays and pathology tests;
- (c) eye tests performed by optometrists;

- (d) most surgical and therapeutic procedures performed by doctors;
- (e) some surgical procedures performed by approved dentists; and
- (f) specified items under the Cleft Lip and Palate Scheme.

## 2.22 What is not covered by Medicare?

Medicare does not cover benefits for:

- (a) private patient hospital costs;
- (b) dental examinations and treatment (though some limited free dental services are available to pensioners, you should contact your local Area Health service for more information);
- (c) ambulance services;
- (d) home nursing;
- (e) physiotherapy, occupational therapy, speech therapy, eye therapy, chiropractic services, podiatry and psychology;
- (f) glasses and contact lenses, hearing aids, prostheses and other appliances;
- (g) acupuncture;
- (h) medicine and hospital costs incurred overseas;
- (i) medical costs for which someone else is responsible (eg. workers compensation);
- (j) surgery solely for cosmetic reasons; and
- (k) examinations for life insurance / superannuation policies.

## 2.23 How do I make a claim?

You can claim in 5 different ways from Medicare.

- (a) Bulk billing - where the medical practitioner claims payment directly from Medicare;
- (b) Claiming by mail - where you send a completed claim form and original accounts/receipts to GPO Box 9822 in your capital city;
- (c) Claiming in person at a Medicare office - where you present your Medicare card and original accounts/receipts for cash, cheque or EFTPOS benefit;
- (d) Claiming by telephone - call 1300 360 460 with your Medicare card number, your account/receipt and the bank details for an electronic credit. You then post the original receipt/account to GPO Box 9847 in your capital city; and
- (e) Easyclaim - This is a dedicated fax facility set up in a number of pharmacies across Australia where you fax claims direct to Medicare. Refunds are then provided by cheque or direct bank credit.

## 2.24 Will I ever have to repay Medicare?

The most common instance when you must reimburse Medicare is when benefits are paid for an injury and you subsequently receive a compensation payment (such as a work related injury, an injury sustained in a car accident or an injury received due to the negligence of another person).

You can claim Medicare benefits while a claim for compensation is being pursued. However, once the insurer has accepted liability for the injury you must cease to claim through Medicare and reimburse Medicare for the benefits paid up to that time from the compensation received. Therefore, before accepting any compensation offer you (or your adviser) should be sure to check with Medicare the amount which must be reimbursed and use this when evaluating the settlement offer being made to you. To obtain information on all services claimed as a result of the injury/illness call the Medicare information line or your nearest office, contact details are listed in Chapter 14 under "Medicare".

## 2.25 What if I have a complaint about Medicare?

Complaints against the Medicare scheme or health professionals misusing the scheme should be directed to the Health Insurance Commission.

Complaints about the professional conduct of individual health professionals (eg. doctors, nurses, dentists, chiropractors) or the clinical management or care of patients by a health service (eg. ambulance service, hospital, aged care facility) are handled by the NSW Health Care Complaints Commission and/or the relevant medical board for the profession involved. Complaints must be in writing and verified by a statutory declaration (witnessed by a Justice of the Peace or solicitor). Both of these bodies investigate complaints 'in the public interest' and can take disciplinary action against a health provider if necessary. Neither of these bodies deals with financial compensation for consumers. You should seek legal advice (such as through a private solicitor, legal aid or a community legal service) if you want to seek compensation for injuries suffered as a result of negligence by a medical practitioner.

Contact details for the Health Care Complaints Commission are listed in Chapter 14.

## 2.26 The Pharmaceutical Benefits Scheme (PBS)

This is a Commonwealth government scheme which subsidises certain prescriptions for all Australian residents and visitors from countries with whom Australia has a Reciprocal Health Agreement (eg. Finland, Italy, Malta, New Zealand, Norway, the Netherlands, Sweden and the United Kingdom).

If you hold a concession card issued by Centrelink or a Department of Veteran's Affairs treatment card, you are entitled to an additional subsidy for PBS medicines.

Generally, you should pay a maximum of \$28.60 for a PBS medicine, or \$4.60 if you are a concession card holder (note, figures are adjusted annually, in line with Consumer Price Index (CPI)). However, you may pay more if you choose a more expensive brand, and the difference for the more expensive brand does not count towards your Safety Net total.

## 2.27 The PBS Safety Net

Similar to the Medicare Safety Net, if you or your family (which includes spouses or de facto spouse, children under 16 years in your care and full-time dependant students) need a lot of medicines in a year, the PBS Safety Net will reduce the cost of these after a threshold has been reached. The threshold varies annually and from January 2005 is \$874.90 for patients and their families in a year, or \$239.20 (52 prescriptions) for concession cardholders and their families.

Once you reach the threshold, you can apply for a Safety Net card and your medicines will be \$4.60 for each prescription for the rest of the year, or free if you are a concession card holder.

To be eligible for the PBS Safety Net you need to keep a record of your spending on PBS medicines. In some cases, your pharmacist may be able to help you keep a computer record of your spending, or you can use a Prescription Record Form available from your pharmacist and ask the pharmacist to complete it each time you make a purchase.

## 2.28 Private health insurance

Private health insurance provides cover for treatment as a private patient in a public or private hospital and for other out-of-hospital services not covered by Medicare. It differs from Medicare in that it:

- (a) covers more out-of-hospital services (such as physiotherapy and dental care);
- (b) covers some of the expenses associated with being able to choose your doctor;
- (c) provides access to a better standard of meals and private room accommodation; and
- (d) provides access to private hospitals for non-urgent procedures for which there may be a waiting list in public hospitals.

Private health insurance is not designed to, and does not necessarily, ensure priority of treatment over public patients.

## 2.29 What options are there?

- (a) Basic hospital cover

This provides cover for treatment as a private patient in a public hospital. It will also provide a small contribution towards treatment in a private hospital, but the bulk of private hospital costs will be borne by you under this level of cover.

- (b) Top hospital cover

This provides for cover in a private hospital. Under some policies, all costs associated with hospital treatment are covered, however this varies between funds and policies and should be checked out as any difference between the level of cover and the fees charged by the hospital will have to be paid by you.

- (c) Ancillary services / extras

This is cover for services such as dental care, natural therapies and physiotherapy, which are not covered by Medicare. Matters you should be careful to check when determining if the policy looks like good value include:

- (i) if there is a maximum annual benefit payable for extras you will be using frequently; and
  - (ii) what the waiting periods are for extras, such as dental and optical, and whether you will need to use these services before the waiting period expires.
- (d) Ambulance cover

This type of cover is usually automatically included in the packages listed above, but it is worthwhile asking when choosing a package.

Private health funds also have combination packages available, with premium costs varying according to the level of hospital cover and the number of extras. Some packages also have a maximum annual benefit which can be claimed for certain extras.

## 2.30 What is an excess?

An excess is another option available to help reduce your premium. It involves agreeing to pay a set amount up front, should you need hospital treatment (such as the first \$500 of hospital costs per year).

### **2.31 What is the 'gap' between benefits and fees charged and when will I have to pay it?**

All consumers should be aware that even the top level of private cover may not cover all actual costs involved in a visit to hospital. You may be left having to pay out of your pocket the gap between the total charged by the doctors and hospital and what is covered by the health fund and Medicare. Before having any medical procedures undertaken, it is a good idea to check with your doctor about whether s/he charges above the government recommended fee (the Schedule Fee) for the procedure. If s/he does, then you should check with your health fund as to whether it will cover the full fee, or if you will have to pay the difference between the scheduled fee and what the doctor charges.

### **2.32 What is the Federal government Private Health Insurance Rebate?**

Since January 1999, the Federal government has offered a 30% rebate on premiums paid for private health insurance. The rebate is not means tested and can be claimed:

- (a) as a reduced premium when paying the fund (you need to register with your fund);
- (b) as a tax rebate when you lodge your annual income tax return; and
- (c) as a direct cash payment through Medicare.

Prior to purchasing private health insurance, you should be careful to check that your fund is registered to participate in the scheme as not all funds are registered and this is a prerequisite to you being able to claim the 30% rebate.

### **2.33 What if I have a complaint regarding my private health insurer?**

Complaints concerning private health insurers, premiums, claims for refunds and other related matters can be made to the Private Health Insurance Ombudsman (contact details are set out in Chapter 14).