

Special rules apply to obtaining consent in people who are under 18 years (See Specific issues in children, Section 13).

An adult patient should initially be presumed competent. Where doubts exist as to his or her competence, you must assess whether the patient can comprehend and retain the information, believe it, and weigh it in the balance to arrive at a choice. In some cases, you may feel it appropriate to involve a psychiatrist in this assessment, although that is not essential in all cases.

Examples of patients who will not be competent include those who are comatose or in a permanent vegetative state (see Permanent vegetative state, Section 7). You may also be concerned about competence where a patient refuses consent for a life-saving procedure - for example, they may be acutely confused as a result of their disease. It is nevertheless important to emphasise that competent adults can refuse consent for any reason or for no reason at all. Refusal of consent by a competent person applies even if the individual subsequently becomes incompetent (see Advance directives, Section 10).

An adult does not need to be competent in all aspects of his or her life to be able to give consent for (or refuse consent for) a medical procedure. In England, no other person has a right to determine treatment decisions for an incompetent adult. If an adult is unable to give consent then a medical practitioner must proceed in what they believe to be that patient's best interests. The doctor must make every effort to determine what the patient would have wanted to happen in the circumstances, perhaps by asking

family members whether the patient had ever expressed relevant wishes. In any event it is both desirable and advisable to consult with immediate family where possible. You should nevertheless ensure that you respect the confidentiality of the patient, particularly in the event that they have refused disclosure to their relatives, for example.

In certain circumstances, it may be felt appropriate to take photographs or video footage of patients. This may be for recording in the medical notes, in order to obtain a second opinion from a colleague, for teaching or for publication. Whether or not the patient can be identified, all photographs must have the patient's consent and they must be told what the images will be used for. The Medical Illustration Department has consent forms for this purpose. For further discussion of this issue see British Medical Journal 1998; 316: 1009-1011. There are also hospital documents about obtaining consent on the RUH web site (see under Hospital policies, Section 18).

## **5. Withholding & withdrawing medical treatment**

The decision about whether or not to start a medical treatment should be made by senior doctors, often in consultation with colleagues such as experienced nurses and after discussion with the patient concerned. If a treatment or investigation is expected to provide benefit to a patient then it should normally be offered, although any competent patient can choose not to receive a treatment or investigation for any reason. If a patient is not competent to make decisions about their care, a senior clinician must make an assessment of that patient's best interests.

The clinician would normally consult with family and close friends of the patient to gain an understanding of their likely preferences, had they been competent (provided that the patient has not, in advance of becoming incompetent, refused their permission for such disclosure).

There is no distinction in law between withholding and withdrawing medical treatment, although medical and nursing staff may feel less comfortable with withdrawing a treatment once it has been started. It is important that treatment should not be withheld on the basis that it will be difficult to withdraw it later; if in doubt such treatment must be started and reviewed when more information (clinical or otherwise) becomes available.

Artificial hydration and nutrition, using means such as intravenous drips for fluid and gastrostomy tubes for feeding, are also considered to be medical treatment. The clinician caring for a patient in whom such treatment is being considered or reviewed must consider the patient's views and whether the treatment constitutes a burden or a harm to the patient. For example, if the patient is very close to death then it might be inappropriate to start aggressive feeding via a gastrostomy tube but intravenous fluids may make the patient more comfortable.

A special case exists for people who are in a permanent vegetative state. In England, Wales and Northern Ireland the courts must be consulted before artificial nutrition or hydration is withdrawn from these patients. The law differs in Scotland.

## **6. Brain death**

Patients who are critically ill with severe brain damage may have their treatment withdrawn if they meet the criteria of brain death as assessed by two senior well experienced doctors. There are strict protocols and guidelines for managing these situations and these are rigidly applied.

A patient who is diagnosed as brain dead is legally dead, even although some bodily systems may continue to be mechanically supported. Patients who will be organ donors receive intensive treatment with artificial ventilation, intravenous fluids and sometimes drugs to support blood pressure, given after the diagnosis of brain death has been made.

Such situations are uncommon and will only arise when patients are being looked after in critical care environments. When these situations do arise critical care nursing and medical staff will provide support to the families and loved ones of these dying patients. Clear explanations will be offered at all stages so that families and loved ones are fully informed of what is happening.

## **7. Permanent Vegetative State (PVS)**

Patients who are in PVS are not brain dead, and are not candidates for organ donation. PVS patients are believed to be in permanent coma, and although they may open their eyes and 'track' visually they lack higher cerebral functioning. Occasionally either a family member or a carer may wish to withdraw treatment of a patient in PVS. In this situation it is necessary to refer the case to the courts for a decision.

## **8. Organ donation**

When patients die in hospital and it is their expressed wish that their organs are used for donation, hospital staff will do their best to ensure that patients' wishes are respected. However, there are strict and rigorously applied protocols concerning organ donation, and not everyone who dies in hospital will be suitable for organ or tissue donation.

There are different circumstances and ways in which organs and tissues can be donated:

### **Beating heart organ donation**

- Patient has to meet formal brain death criteria (see above).
- The organs to be used must be in good condition.
- There are some circumstances in which organs may not be suitable for transplantation.

### **Non beating heart organ donation**

- This is not performed in many centres at the moment (the RUH is considering doing it on a trial basis in consultation with the UK Transplant Authority).
- Very specific criteria have to be met and a team of experts is needed to undertake the work required. These experts may not always be available.
- Not all patients are suitable for the donation of organs in this way.

## **Tissue donation**

- Some tissues such as heart valves, bone, corneas and even skin may be donated.
- Strict protocols apply and not all patients will meet the criteria.

## **Bequeathing a body for medical research**

Sometimes a patient requests in their will that their body be used for medical research. All of the paperwork for this will generally have been completed as part of the process of drawing up the will. However, there are many obstacles to a body being accepted, and so not all requests can be met. There may be some additional costs to the estate.

Hospital staff will always try to help families and loved ones to meet the expressed wishes of patients who die.

## **9. Tissue retention**

Retention of tissues for teaching or research is not allowable without the explicit consent of the patient before death or, if unavailable, from their next of kin after death. This includes coroner's postmortems, when consent for the postmortem itself is not required. The future position regarding retention of tissue blocks and slides is yet to be clarified, but for the present the advice is to seek consent for retention of all human material. Guidelines are available from the Chief Medical Officer and additional legislation is expected in the near future.

## **10. Advance directives**

Increasingly, patients are expressing their preferences for future treatment in Advance Directives. Advance Directives are relevant if the patient is no longer able to make decisions on their own behalf (competence; see Consent, Section 4). You must comply with an Advance Directive if you believe, in good faith, that the patient expressed his or her wishes while competent and sufficiently well informed and that the directive applies to the situation that has arisen now that he or she is incompetent.

An Advance Directive should therefore be taken to express the wishes of the competent patient if the clinical situation has been anticipated. If the situation differs, the Advance Directive may give hints to the patient's wishes, but cannot be taken to be a comprehensive instruction; in such circumstances, the doctor must act in what they see as being the patient's best interests, taking all factors into account.

## **11. Good communication & breaking bad news**

It can be the case that what appears to be a difficult ethical situation is in fact the product of poor communication. Good therapeutic communication is essential to successful patient care and this is particularly true when a member of staff has to give information to a patient that is likely to cause distress.

Consider the following points when breaking bad news:

- Know the relevant facts, arrange for privacy, sufficient time and ensure the patient is accompanied.

- Find out first what the patient understands.
- Allow the patient time to digest the information. Give the information at the patient's pace and know when to stop.
- Speak clearly but not simplistically. Avoid euphemism, jargon or technical terms. Be gentle, warm and sensitive to their feelings. Assume nothing and check that the patient understands things as you go along and at the end.
- Summarise the plan for the future. The impact of bad news will significantly disrupt short-term memory so document all relevant points.
- Never deny or avoid the patient's feelings. Do not tell them not to cry or express emotion.
- People usually cope very well with the truth of their disease, but require information and support to do this.

It is impossible to break bad news in a manner that conceals its 'badness'. Even if you do it well, you may still cause distress.

## **12. The role of patients' advocates & the chaplaincy**

Within the context of medical ethics, the chaplaincy seeks to provide clinicians, patients and the clinical ethics committee with the following resources:



- Helping clinicians to make decisions about a patient's care that are appropriate to that patient's own cultural, religious and social traditions. Interpreting ideas of autonomy, benefit and welfare in the context of those traditions.
- Understanding a patient's subjective experiences and how those experiences relate to treatment options in health, disease, disability or impending death. The chaplaincy team may assist decision making between those options by ensuring mutual understanding of the teaching and direction of a patient's religious or cultural traditions.
- Helping in discussions about whether the intended clinical actions are truly patient centred. Understanding the wider implications for the patient, their family and community. It is not uncommon in clinical practice that issues about a patient's religious or spiritual practices require consideration as part of clinical care. This is especially common when these views are in conflict with clinical or legal restrictions.
- Providing a professional advisory service about religious and cultural traditions as they affect clinical decision-making processes and patient autonomy.
- Providing insight into spiritual and emotional pain and how such suffering affects the way that patients make decisions in different faith communities.

### **13. Specific issues in children**

All children under the age of 16 who require overnight admission to the RUH are admitted to the Children's Ward. Young people of 16 years or over should be offered the choice of whether they attend the Children's Ward or an adult ward if they are still in full-time education.

Although young children may not be able to fully understand their illness and treatment, they should be involved as much as possible and given simple explanations of what is happening to them. Where they are able to state preferences about their care, these should be listened to. Decision-making ability depends on experience as well as age and intelligence, so children with chronic diseases may be able to make important decisions at younger ages than children who are ill for the first time.

Young people who have reached the age of 16 but are not yet adults (i.e. are aged under 18) can consent to their own treatment. In order to assess whether or not these patients are competent to consent, you should apply the same test as you would apply to adults (see Consent, Section 4). It may be the case that young people between 16 and 18 years are not legally **considered able to refuse consent**.

Young people who are under 16 can consent to their own treatment, provided that they are 'Gillick competent' - in other words, of sufficient understanding and intelligence to comprehend the nature of the treatment, its risks, benefits and side effects. But they cannot legally refuse treatment that their doctor feels is in their best interests and that their parents have consented to. To be 'Gillick competent' the child must be able to comprehend and retain the

information given and weigh up the options in order to come to a decision. Where the child is not competent then parental consent is required.

Parental consent can be given by anyone who has parental responsibility. The child's birth mother automatically has parental responsibility but the father will only have it if he is married to the mother or has made a parental responsibility agreement with the mother or obtained a court order granting him parental responsibility. If the child is living in care, parental responsibility may be with the birth parents or with the local authority. Adoptive parents have parental responsibility, as do guardians appointed on the death of a parent.

If no one with parental responsibility is available to give consent, treatment that is necessary in the child's best interests, particularly lifesaving treatment, can be given. If two people with parental responsibility disagree, the doctor can legally treat the child with the consent of the parent who agrees with the doctor, but consensus should be reached if at all possible. If parents refuse to consent to what the doctor feels is in the child's best interests, all possible steps should be taken to resolve this. Using the courts should be a last resort.

For more information, the BMA publication 'Consent, rights and choices in health care for children and young people' is very useful.

#### **14. Specific issues in the elderly**

The same principles regarding confidentiality, consent and best interests apply to elderly patients as to other adult

patients. However, elderly people are a special case in part because of their vulnerability or potential vulnerability. When elderly patients are dependent on family or carers, confidentiality can be difficult to maintain. It is a common misconception on the part of family members and doctors that consent can be taken directly from adult children; in fact, this is not the case. Instead, as with other adult patients, if the elderly patient is not competent to decide for him or herself, decisions must be taken on the basis of his or her best interests. There is a risk that best interest decisions are taken without reference to elderly patients' previously expressed wishes. Medical staff should be meticulous in ensuring that they are afforded the same respect and protection as younger patients.

### **15. Specific issues in the mentally ill**

As mental illness affects the mind of the individual, a wide range of ethical issues can arise. Confidentiality and capacity are already covered, and have to be considered frequently in working with people suffering mental illnesses. Insight and judgement may well be impaired in severe illness, raising issues about the possible need to invoke the Mental Health Act (MHA). This legislation is complex, and potentially gives psychiatrists enormous power over patients, so has to be used correctly and wisely. The current MHA does not include 'capacity' or lack of it as a defining principle guiding the use of the act. It therefore has little to do with competence and focuses much more on compliance (or lack of it).

The MHA allows a patient to be detained in hospital if certain strict criteria are met. Two doctors (one of whom

must be 'approved' - usually a senior psychiatrist) and an 'approved' social worker must all agree that those conditions are met (seriousness of illness, risks to self or others sufficiently great and no reasonable alternatives). Within very defined regulations treatment can be given to patients detained under the MHA. This treatment can only be for the mental disorder or anything directly linked to it, its symptoms or cause (e.g. use of antibiotics in toxic confusional states, or rehydration of a patient with severe depression).

It is important to remember that mental illness does not disqualify sufferers from taking part in discussions over their welfare and treatment. Neither should their ideas and feelings be discounted, even (perhaps especially) if they are detained under the MHA, or suffering from a dementing illness. In the interests of giving patients as much autonomy as possible, methods of enhancing capacity should be explored. Patients with mental illness may have fluctuating symptoms, and decisions from them should be sought during a 'lucid interval' or other change in state (e.g. diurnal variation in severe depression).

Doctors and other clinicians have moved on from a culture of doing things **to** patients to one of doing things **with** patients and this applies as much in psychiatry as it does in any other speciality.

## **16. Jehovah's Witnesses & blood products**

Jehovah's Witnesses belong to a branch of Christianity who believe that receiving blood from another person is forbidden by God. The products that they do not accept are

transfusions of whole blood, packed red cells, white cells, plasma and platelets. Preoperative autologous blood collection and storage for later infusion is also usually unacceptable. Individuals may or may not accept intraoperative cell salvage, heart bypass, haemodialysis and haemodilution, and fractions of plasma or cellular components such as albumin, immunoglobulins, vaccines and haemoglobin-based oxygen carriers. When a Jehovah's Witness requires treatment where blood products would normally be given, non-blood alternatives should be considered and it may be necessary to consult with colleagues who have had previous experience of non-blood management of the condition in question. For those under the age of 18 serious consideration should be given to care proceedings when blood transfusion is refused. (See Specific issues in children, Section 13). There are local hospital liaison committees of Jehovah's Witnesses (the nearest to the RUH is Swindon) who are available to provide advice. The RUH has produced guidelines on the treatment of Jehovah's Witnesses, which is available on the RUH web site (see Hospital policies, Section 18).

## **17. Treating prisoners**

Very occasionally prisoners may come to the RUH for treatment. Prisoners are entitled to the same standards of medical care as any other patient and are entitled to the same level of confidentiality. Often the prisoner will arrive handcuffed to a prison officer. In these circumstances, the BMA ethics committee recommends that prisoners be examined without shackles or restraints and without prison officers present unless there is a high risk of violence or escape. It is usually the case that a value judgement must

be made as to the risk a prisoner poses as against their right to privacy but this is often difficult. As the treating doctor you are entitled to request the removal of restraints “at the point where treatment begins”. If continued restraint is necessary, you must try to treat the patient with as much respect, privacy and confidentiality as possible. For further discussion see BMJ 2002; p324; supplement p11.

## **18. Hospital policies**

### **Do Not Attempt Resuscitation (DNAR) Orders**

The RUH Trust has a DNAR policy, which can be seen on the RUH website. The following is a summary of this policy.

Cardiopulmonary resuscitation (CPR) is a technique used to restore spontaneous circulation in individuals who suffer cessation of cardiac or respiratory function (cardiac or respiratory arrest). CPR is undertaken when it is thought possible to restore a patient to life of appreciable duration and quality. It is not appropriate to attempt resuscitation if the competent patient has refused such resuscitative efforts in advance, or if the cardiorespiratory arrest has occurred as the final event in the process of dying. The outcome for in-hospital cardiopulmonary resuscitation is poor. Fewer than one in six patients will survive to go home. Some patients will survive with permanent brain impairment. The outcome for patients who suffer cardiorespiratory arrest as part of ongoing unrelated disease is dismal.

A decision should be made about resuscitation before a cardiac or respiratory arrest occurs and, if the patient is competent, should be made with the patient. This decision

must be made at specialist registrar level or above. If the medical staff or the patient consider attempted resuscitation to be inappropriate, then a DNAR statement must be placed in the patient's notes, signed and dated. Any such order applies only to the current admission and it should be reviewed regularly.

If no such order has been written, and the wishes of the patient are unknown, it is expected that cardiopulmonary resuscitation will be initiated. The medical team is not obliged to commence CPR if they believe that such efforts are futile and not in the best interests of the patient. A DNAR decision in no way implies withdrawal of patient care. All medical and nursing care appropriate to the patient should be continued.

### **Retrieval of gametes from dying males**

The RUH Trust has a policy for this rare request, which can be accessed via the RUH website. The removal of gametes is unlawful unless there has been prior consent by the man for this procedure. The procedure is not funded by the NHS and therefore can only be carried out by special arrangement. It requires an appropriately trained clinician to be available at the time.

### **Obtaining consent**

Supplementary information can be accessed on the RUH web site.



## Care of Jehovah's Witnesses

Supplementary information can be accessed on the RUH web site.

### 19. Glossary of terms

**Advance Directive** - also known as a 'living will'. This may take the form of a document in which a person presents their view of what medical treatment they would wish to have were they unable to make their wishes known at that time. An Advance Directive is applicable to the circumstances anticipated within it.

**Best interests** - Adults may become incompetent to decide their own treatment. If this occurs, there is no facility in England for one adult to nominate another in advance to make proxy treatment decisions. In the event of an incompetent adult requiring treatment, the doctor must act in what they believe to be the patient's best interests. It is advisable before making such decisions to consult widely with those who know the patient well, in order to gain an understanding of the patient's own values and likely wishes. A decision to treat or not treat a child may also need to be made on the basis of the child's best interests; for example, this may occur where the child and/or his or her parents have refused to consent to treatment. Nevertheless, in some cases it may be advisable to refer the decision to a court, which will itself determine what is in the child's best interests.

**Brain death** - clinical diagnosis made where a patient is ventilator dependent with continuing circulatory function but irreversible lack of cerebral function.

***Clinical Ethics Committee*** - a multi-professional committee set up to give ethical advice to staff regarding individual patients, to provide education, and to advise on hospital policy.

***Competence*** - the ability to understand information, retain it, believe it, and use it to make decisions about health care.

***Competence, Gillick*** - this refers to the legal position of taking consent from children under 16 years and derives from the decisions made in the case of Gillick vs West Norfolk and Wisbech AHA, 1986

***Consent, Informed*** - the consent of a patient to medical treatment after they have been given all relevant information about the risks and benefits of the proposed treatment

***Futility*** - Doctors are not required to carry out a treatment if it is not expected to provide benefit to a patient in terms of length or quality of life. Such treatment would be considered futile, and carrying it out could be considered an assault.

***Parental responsibility*** - legal responsibility for a child held in most instances by a child's mother and father, but see Specific issues in children, Section 13 for exceptions.

***Permanent vegetative state (PVS)*** - a state of permanent coma, where the patient is irreversibly unaware of him/herself and his/her environment. Although patients may open their eyes and 'track' visually, they have a total loss of higher cerebral functioning.

# Decisions Relating to Cardiopulmonary Resuscitation

A Joint Statement from the British Medical  
Association, the Resuscitation Council (UK)  
and the Royal College of Nursing

# Decisions Relating to Cardiopulmonary Resuscitation

A Joint Statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing

*All establishments that face decisions about attempting resuscitation should have in place local policies for decision making.*

*The purpose of these guidelines is to outline legal and ethical standards for planning patient care and decision making in relation to cardiopulmonary resuscitation.*

*The focus of the guidelines is situations in which decisions are made in advance and form part of the patient's care plan. Emergency situations where no advance decision has been made are also covered.*