Confidential

Children's consent to medical treatment

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BMA

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Introduction

The reason for the report

The British Medical Association has always received many enquiries from doctors about ethical and legal aspects of examining and treating children and young people. The flow of such enquiries increased during the 1990s and continues to rise. A range of diverse factors contributed to this. Part of the growth in queries can doubtless be attributed to increased awareness of children's autonomy and the importance of health professionals providing minors with clear information. Changing perceptions of the rights of the child also raised questions about the role of parents and other agents with parental responsibility, particularly in relation to decisions about treatment for mature young people. The boundaries of confidentiality, both in terms of individual minors and in terms of the family's privacy, generated a substantial number of questions. A further area of concern has been the involvement of children and young people in procedures, such as medical research or tissue donation, which are not intended primarily for the benefit of their own health. In this report, the BMA sets out its views on the ethical issues most commonly raised by doctors.

The law

Also apparent in the queries consistently raised with the BMA is some uncertainty about aspects of the law regarding consent and refusal of treatment in relation to children and young people. With the assistance of an expert steering group and other eminent contributors, the Association has considered both statute and case law in this area. Illustrative examples have been drawn from case law and feature in most of the chapters. The book covers the law in England, Wales and Northern Ireland.[1] The guidance does not extend to Scotland where the law is significantly different.[2]

As yet, the likely impact of the Human Rights Act 1998 on medical practice is unclear. The UK Act incorporated into domestic law the European Convention on Human Rights. Although it may not seem immediately relevant to medical treatment, the European Commission has already held that experimental medical treatment may amount to inhuman treatment in the absence of consent. It has also been argued that the an application under Act's 'right to life' provision could effectively overturn the precedent set by a 1995 Cambridgeshire case, where the Health Authority refused to fund expensive medical treatment for a child, which was only likely to prolong life for a brief period. Legal issues are considered in chapter 2 of this report and in the interests of providing practical advice, this reflects advice on areas where the law is more established. While noting that the potential effect of this new Act remains a matter of speculation, it may, nevertheless, be relevant to note that some lawyers are predicting that the Act will produce a new way of thinking about rights and freedoms. If so, this may lend even more strength in future to the moral arguments in support of the rights to self determination of mature minors. In the meantime, this report flags up situations in which health professionals are likely to need to take specific legal advice.

The aim of the report

The aim of the report is to provide guidance which is as clear and as practical as possible. Because it reflects their questions, it is intended primarily for health professionals but has also been drafted to be accessible to patients, their families and other people with an interest in these issues. The report aims to summarise the current ethical approach to consent, refusal and confidentiality in respect of provision of health care to children and young people. It also summarises the law in England and Wales on these same issues, identifies areas where the legal position is unclear and offers advice on those circumstances.

In order to get a rounded debate on the practical problems and informed opinion about solutions, the BMA established an expert steering group, whose membership is given below. It also took written and oral evidence from a wide range of contributors about the management of both routine and exceptional cases. One aim is to show how the same ethical principles which underpin good routine practice apply equally in many of the hard cases. Although, practice must not be driven by exceptional, particularly complex cases, these inevitably challenge health professionals and families and need to be taken into account. Therefore, attention is given in the report to the relatively rare cases where profound disagreements arise and conflict has to be managed in a way which maximises benefit and minimises harm.

Inevitably, any analysis of concepts such as "benefit" and "harm" raises complex moral questions which, although fascinating in themselves, may not provide practical assistance to practitioners and patients. Nevertheless, the report seeks to show briefly how, within medicine, understanding of concepts such as benefit and harm have widened very much beyond the relatively straightforward measurement of purely physical health indicators to include concepts such as psychological and social harm. In brief, in exceptional cases, overriding an informed minor"s wishes may produce a health benefit but at the cost of other kinds of harm, including loss of trust and a break-down in cooperation. Clearly, this does not mean that health professionals or parents can never act against a minor's wishes but rather that the full dimensions of the harms and benefits that flow from the decision need to be carefully weighed by all those involved in making it, including the child. While flagging up these moral issues, however, our principal aim remains the provision of clear and practical guidance in order to identify a way forward in such cases.

How to use the report

As we envisage that readers may wish to dip into the report with a specific question in mind rather than read it in its entirely, each chapter is designed to be free standing and convey as complete a picture as possible. This inevitably means that there is an overlap between chapters and repetition of some core points in each. For example, a point repeatedly emphasised throughout is the importance of children and young people being as fully involved as possible in all health care decisions which affect them. We also repeatedly emphasise the general desirability of shared decision-making between patients, parents and health professionals while acknowledging that this is not always feasible. A summary of main points is included at the end of each chapter but we would encourage readers to consider the discussion sections relevant to specific summary point rather than consult the summary alone. Further details of the legal cases described can be found in published law reports, as referenced.

Other relevant BMA guidance

The project drew on other work undertaken by the BMA during this period. In 1999, for example, the BMA published general guidance on confidentiality, including the rights of minors to control medical information about themselves. It also published guidance on refusal, withholding and withdrawal of life-prolonging treatment. A section of this concerned treatment decisions in relation to children and young people. Also in 1999, the BMA published 'Our Children's Heath: Improvements for the Future', focussing on clinical aspects of child health. In 2000, a separate BMA report on the clinical management of anorexia and other eating disorders was published.

1. In the main, the law is the same in the Channel Islands and the Isle of Man.

2. In the meantime, queries relating to the law on issues raised in this report should be directed to the BMA Ethics Dept.

Chapter 1: An ethical approach to treating children and young people

1. Putting decision-making in context

The purpose of this chapter is to consider the ethical framework within which questions of children's consent and refusal need to be considered. Some fundamental points can be made at the outset. The first is that the ethics of providing care and treatment for minors are the same in most respects as the ethics of treating any other patient. All patients are individuals whose interests need to be considered in a holistic manner, which takes account of their own firmly held wishes as well as their physical needs. Routine care, such as immunisation programmes, and difficult dilemmas, such as whether to prolong invasive treatment for a chronically ill child, must take account not only of medical factors but also the competent patient's wishes and those of the family.

This raises the second point which is that minors, like many other patients, generally live in networks of emotional relationships that are important to them. In the case of children, it is often difficult to focus on the patient's best interests when these are intertwined with and shaped by those of their families. In the majority of cases, however, the interests of all coincide. Circumstances in which this is not the case, such as when young people wish to exclude their parents from information or when parents may pressure children to undergo controversial treatment such as organ donation, are considered in later chapters. In most cases, parents have the best interests of their child in mind. They are usually the best placed to decide on treatment options for young children and should be closely involved in decision-making with mature children, wherever this is consistent with the principles of confidentiality and patient choice, explored in this report.

The third point concerns the the role of the wider society which also has an interest in ensuring that children are properly cared for, not put at risk and their rights are balanced with those of other people. As is discussed in this chapter, societal attitudes to minors are somewhat ambivalent: competent children's rights to self determination are much debated but such rights are usually curtailed as soon as it appears that a child's health might be jeopardised. This is one respect in which the ethics of treating children differ significantly from those of treating adults, where patient autonomy allows for treatment refusal even when death results. In the case of minors, the courts provide an ultimate arbiter and can override a child's or parents' refusal of a particular treatment, if there is evidence that it would physically benefit the child. It is not the intention of this report to argue in favour of more risk-taking attitudes but rather to draw attention to some of the ambiguities that health professionals face in meeting society's expectation that they should both empower and protect young people.

Although these really complex ethical problems arise when there is a clash between the expressed views of parents and of children, or where one or other of those also clashes with professional opinion, these are more the exception than the norm. Very few decisions about treatment are of the life and death variety and very few have to be decided in a hurry. Good practice is based on good communication and the establishment of trust between the patient and the health team. All children as soon, as they can communicate and understand, should be involved in a dialogue about their medical problems. Through every stage of their development, they should to be encouraged to talk to health professionals, as well as to their families, about how they feel concerning treatment options. It is essential that children and young people are shown that their views are valued and that those views will be treated confidentially, on the same terms as dialogue with adult patients. (Chapter 3 considers both the scope and limitations of the duty of confidentiality.)

Defining the patient group

In law, the term 'child' or 'minor' covers everyone under the age of 18, from the newborn to the young adult. There is a growing convention of recognising people of approximately 12 years and over as "young people", rather than "children". [1] Even if we divide minors by rough chronological age, the range of ability, awareness, insight, judgement and experience in each group is immense. Life experience and mastery of decision-making skills vary considerably even within age cohorts and do not necessarily match the expectations society has about individuals' chronological age. In fact, we often under-estimate the abilities of children, particularly those as young as five years old and under, to understand what is at stake and take a significant part in decisions about their health care. (Issues of competence are discussed in Chapter 4). What is clear, however, is the growing recognition that this very diverse group of individuals who are classified as 'minors', do have a collection of moral rights. Bearing in mind the fact that some of these are likely to be interpreted differently to the rights of adults in relation to medical treatment, it is nevertheless important to recognise those upon which there is clear international consensus.

Recognising minors' rights

The UN's 1989 Convention on the Rights of the Child is the most widely endorsed statement of children rights. (Appendix X). In 1991, the UK ratified the Convention, providing an opportunity for the development of rights-based and child-centred health care. In 1995, the former British Paediatric Association (BPA, now the Royal College of Paediatrics and Child Health) published a paediatrician's guide to the Convention[2] which welcomed it as an opportunity for paediatricians and other health professionals to work towards a paradigm shift within society on the matter of children's healthcare rights. The guide focussed on rights such as the child's right to "the enjoyment of the highest attainable standard of health", the right of competent children to make informed choices and the right of confidentiality. The BPA pointed out how the basic "right to health" was breached by widening inequalities in child health, with poverty and deprivation contributing significantly to the risks of infant and childhood mortality and morbidity.[3] It called upon doctors to help identify children at highest risk of sub-optimal health, including those whose families were on low incomes and the homeless. The BPA also particularly highlighted Article 12 of the UN convention which obliges health professionals to seek the opinion of children and young people before taking decisions which affect them. It emphasised that children should be informed of the nature of the treatment and be involved in choices about alternatives. These rights were said to be "particularly important in children with chronic illnesses such as cystic fibrosis, diabetes, cancer or renal failure". Various other rights listed in the Convention have a direct relevance for health care, including Article 16 on the child's right to privacy and Article 23 which articulates the rights of children with disabilities to be helped to achieve social integration and individual development.

Children's moral rights in the health sphere are are set out in statements such as the 1998 World Medical Association's Declaration on the Rights of the Child to Health Care. (Appendix X). This statement also gives general recognition to a range of minors' rights, including the rights to care and protection and the rights of self-determination and freedom of choice.

An inherent problem in any statement of rights, however, is that there is no widely agreed way of ranking different rights that may not sit easily with one another, or balancing one person's rights with those of other people, such as parents and siblings. While, it must be noted that there is considerable support in medical ethics for the notion of self-determination trumping all other rights, this is usually limited to the treatment of adults. Logically, however, the closer an individual child is to being able to do what adults do - in terms of understanding and reasoning - the more the moral weight should shift towards prioritising that person's right of self-determination. The implications of this view and the need for overall moral equipoise are the subject of this chapter.

Nevertheless, it is important to recognise that autonomy and self- determination are not the only moral rights or even necessarily the most important ones for all children. Picking up some of the points emphasised in the BPA document mentioned above, the BMA has, for example, called attention in the past to discriminative practices which effectively exclude some children, such as those with Downs' Syndrome, from even being considered for some forms of life-prolonging medical treatment. Recognising the increasing numbers of young refugees and asylum seekers in Britain, including increasing numbers of unaccompanied minors applying for asylum, the BMA has also highlighted the need for equity of access to health services for cultural and ethnic minorities and disadvantaged families. The right to consent and refuse treatment -which is our basic concern in this report - must be seen within a wider framework of rights which respect children as whole individuals. Clearly, their rights extend beyond issues about their ability to understand and rationalise.

Summary of children's basic health rights:

- the right of access to child-centred health care;
- the right to be looked after appropriately, without discrimination of any kind including on grounds of disability;
- the right to be encouraged in every way possible to develop one's full potential;
- the right to receive information about matters closely affecting oneself and the right to decline detailed information at a particular time;
- the provision of opportunities to express opinions without pressure or criticism;
- the provision of support and encouragement in decision making;
- clear explanations of the options, the risks and the alternatives;
- the right to ask someone else to decide a particular issue;
- an explanation of the reasons when the child's preference cannot be met;
- the right of confidentiality.

Role of the family

As mentioned at the beginning of the chapter, when providing care and treatment for children, it can be hard to make a rigid distinction between the best interests of the patient and those of the family. The whole family's emotional and psychological welfare is likely to be intimately linked to the child's prognosis and similarly, the child's sense of wellbeing may be affected by the family's attitude. There is now consensus[4] that, from a young age children ought to be consulted and involved in health care choices. This does not necessarily mean that they are the sole decision makers as much depends both on the degree of understanding they show and their willingness to undertake such responsibility. In reality, most health care decisions for minors are taken within a tripartite relationship between the patient, parents and health professionals.

The health team has a duty to ensure that the child's contribution is not overlooked and that the patient has the information necessary to form a view. The child's right of confidentiality and right to control access to his or her health record must also be recognised even though this may cause tensions within the family. (Confidentiality is discussed in Chapter 3). Health professionals need to be aware of children's rights as they should act as the child's advocate whenever it seems that the patient's views are not fully represented within the decision-making process.

Children's ability to grasp what is involved in the treatment choice is the principal criterion as to whether or not their views have a major effect on that decision. (Assessment of competence is discussed in Chapter 4). Nevertheless, even when they do not fully understand, children still have a right to be told what they want to know about their health care and helped to express their views about that. Adults should make genuine efforts to accommodate the child's preferences, where possible. This needs to be done, however, within a treatment plan which takes account of all the rights of the child and of the family. In practice, serious decisions for patients of any age are seldom made in strict isolation but with the support of other people, such as friends, partners, families, carers and health professionals. Adults choose whom they wish to involve in the decision and mature minors can also generally claim this right.[5] For young children, the expectation is that parents are the appropriate primary decisions makers. In the vast majority of cases, they know the child better than anyone and are the best judge of where the child's best interests lie.

"Best interests"

An important consideration in decision making concerns how the individual's "best interests" are defined. A person's best interests are usually served by measures which prolong life or prevent damage to health. Health professionals are accustomed to measuring benefit primarily in terms of physical gains. Thus, where medical treatment carries low risk and offers substantial benefit to the patient, it is clearly perceived as being in the person's interests. Unfortunately, many choices are not that simple. The side effects and other burdens of treatment may not be matched by a genuine prospect of significant and sustained improvement. Alternatively, the promise of physical improvement may necessarily involve compromises which the patient considers unacceptable, such as the administration of blood products to a Jehovah's Witness. It is increasingly recognised that an assessment of best interests must involve far more complex matters than physical criteria alone. While not wishing to reduce such complexity to the level of a checklist, it is clear that a range of general factors, including social and emotional elements, need to be considered when assessing a young patient's best interests in relation to treatment.[6]

Factors to be considered when assessing best interests

- The child's own ascertainable wishes, feelings, and values;
- The child's ability to understand what is proposed and weigh up the alternatives;
- The child's physical and emotional needs;
- The risk of harm or suffering for the child;
- The views of parents and family;
- The implications for the family of treatment or non-treatment;
- Relevant information about the patient's religious or cultural background.
- Evidence of the effectiveness of the proposed treatment, particularly in relation to other options;
- The prioritising of options which maximise the child's future opportunities and choices;
- Evidence concerning the likelihood of improvement with treatment;
- Evidence about the anticipated extent of improvement;
- Risks arising from delayed treatment or non-treatment.

This is not intended to be an exhaustive list but it features fundamental principles that should be considered in any effort to make decisions affecting children and young people. Underlying it is the belief that children are generally best cared for within the family. The BMA recognises the importance, wherever possible, of ensuring that the wishes of children and young people have family support and acknowledges the significance of emotional, as well as the intellectual development in young patients. In some cases, however, children and young people may appear uncertain of what they want to happen. Wherever possible, they must be given the time and support to assist them make a decision that they feel comfortable about.

2. Consent to and refusal of medical treatment

What consent and refusal entail

The law on consent is explained in Chapter 2 but can be briefly summarised as supporting the right of any informed and competent patient to authorise a medical procedure, once the implications, side-effects and alternatives have been appropriately explained. Age is not a determining factor for valid consent. Over 16 years olds are assumed to be capable of consenting on their own behalf but this does not imply that those under 16 cannot give valid consent. Parents give consent on behalf of babies and young children. In most situations, it is desirable to have parental consent in addition to the patient's own so that the family is able to support the young person in making the treatment decision. Nevertheless, on sensitive matters such as obtaining family planning advice, termination of pregnancy, treatment of STDs or addiction, young people are frequently reluctant to allow parents to be informed, despite encouragement from health professionals to do so. (See also Chapter 7 on sensitive and innovative procedures and Chapter 3 on confidentiality).

Consent can be verbal, written or signalled by acquiescence by a person who understands what will be undertaken. Absence of refusal, however expressed, may therefore constitute consent as long as the person understands the procedure to be undertaken and its implications and is aware that rejecting it is an available option. Acquiescence when the person does not know what the intervention entails or that there is an option of refusing it is not "consent". Nor is a mere signature on a consent form proof of valid consent. The moral importance accorded to the signature is entirely dependent upon the quality of the information which has been provided and the recipient's understanding of that information.

Children can sometimes refuse treatment because their anxieties are focussed on one aspect of it that may not be the most important element. For example, the short-term fear of an injection which is necessary before a bigger procedure, such as surgery. They are not expressing a considered choice in favour of non-treatment and they might willingly accept the intervention if administered differently, or if they were given anaesthetising cream before the injection. Genuine refusal of treatment is based on awareness of the implications, is consistent over time and compatible with the child's view of his or her best interests beyond the short-term. In cases where non-treatment will necessarily result in grave harm, suffering or death, society requires the patient to have a fall understanding of all the implications and details.

Morally and logically, competence to consent and to refuse should be two sides of the same coin. The degree of understanding required for any decision must be commensurate with the gravity of the matter being decided. In some cases, a greater degree of understanding may be required to refuse a potentially life-prolonging therapy than that required to consent since the implications of refusal are likely to be more serious. There are exceptions, however, when consenting may require even more understanding than declining. Consenting to a risky procedure may be equally hazardous as refusing an innovative therapy whose full effects may be unpredictable. Outside the sphere of life-prolonging treatment, an example of treatment for which consent requires a very high degree of understanding is surgery for gender re-assignment. Where young people desire such treatment, they would be expected to demonstrate a very thorough awareness of the implications for their whole lives.

Nevertheless, although agreement to treatment can be an even more serious matter than refusal, society appears to set a separate legal standard for young people wishing to refuse treatment and this is discussed further in Chapter 2.

Why we value patient consent

Modern medical ethics sets great value on self-determination and respect for patient choice. Individuals are encouraged to take responsibility for their own welfare, by for example, receiving information that will help them prevent illness. It is desirable for patients of all ages and abilities to have a voice in decisions about their health and be able to exercise control about what is done to their bodies. Health professionals have a duty to take all reasonable steps to enhance patients' ability to do this. Law and ethics also require that treatment of children and young people must be based on an assessment of their best interests. Although in the past, this was often interpreted only in terms of striving for measurable clinical improvement, regardless of the patient's priorities, it is now recognised that a strong element of any person's best interest is that one's own choices and preferences are respected.

Consent is usually a process rather than a single event. It has a practical importance. Compliance with a treatment regime is more likely when patients understand the reason for it and take responsibility for maintaining their health. In many areas of treatment, compliance with a long-term regime of healthcare is essential to its success.

When can patients refuse treatment?

Clearly, real choice involves the option of making what might be perceived as bad decisions as well as allowing people to choose options, which others consider to be wise.

Adults are acknowledged to have very clear moral and legal rights to make unwise decisions. They can choose, within the limits of what they are offered, things which will foreseeably harm or disadvantage them. As long as they are mentally competent, the only limits on adults' choices are the duty to act within the law and not damage others. Only if there is evidence that adults have been wrongly informed or-suffer from impairment to their judgement or mental faculties, do others feel justified in intervening without their consent. So, when an adult patient makes a medical decision which appears conducive to self harm, the issues upon which health professionals must satisfy themselves are whether the decision is within the law; whether it harms other people; whether that person has sufficient mental competence to make the particular decision and whether enough information about it has been provided. This is also the starting point for decision making by children and young people under the age of majority.

Minors face a more complicated situation than people over 18 who can refuse treatment for reasons that are good, bad or for no reason at all. In practice, minors can only usually refuse a very limited range of interventions. A refusal is most likely to be respected when the child clearly understands the nature and implications of the particular intervention and the treatment is not seen as crucial to the child's welfare at that time. This means that there is a sliding scale of measures which a child may be able to refuse. The medical procedures which are least essential to the child's well-being are generally the most amenable to an informed refusal. Those which are immediately life-prolonging or essential to maintain the child's health are least likely to be withheld, simply on the basis of child's refusal. In the latter case, questions arise about the child's competence and moral authority to make such a grave decision. Ultimately, the matter may need to be referred to the courts. (See Chapter 2).

Assessing validity of refusal

- The child must have both the information and the competence to make the particular decision in question.

- All the arguments should be aired and misperceptions or errors of fact discussed.
- The degree to which a refusal conflicts with the child's welfare and overall best interests must be considered; some treatment refusal may coincide with a holistic view of best interests;
- Decision-making should be open to question when it is seriously awry by the usual standards of what a reasonably prudent person in the patient's position would choose. Issues such as the child's desire to protect or please or punish other people should be addressed.
- Until there is evidence to the contrary, the presumption is that parents have the child's best interests at heart;
- Adults retain a duty to intervene if the child appears to be exploited and/or abused or pressured by others. Emotional pressures on the child should also be addressed;
- A mechanism, such as referral to court, must exist for intervening in extreme cases if the child's decisions appear dangerous or seriously damaging.

Ideally, however, medical decisions are best made in partnership between the patient, the family and the health team. The parental role as primary decision maker gradually fades as the child develops in maturity although the importance of parents as a source of emotional support and advice should, ideally, remain.

Why are mature children treated differently to adults?

Discussions about children's consent to medical treatment tend to be dominated by the twin issues of whether children are competent to make informed decisions and whether, even if they are competent, it is right to allow them to make serious and difficult choices.[7] In fact, society at large can be said to wish to promote mutually incompatible values when it emphasises the right of informed and mature young people to make autonomous decisions but, at the same time, insists on protecting them from the effect of those decisions. Society often adds an additional hurdle for children who wish to decide for themselves. As well as demonstrating their competence to understand the implications of the choice, they must also reassure those around them that they can make the "right" choice. In practice, this has tended to mean that their views are only likely to be implemented when they conform to other people's notion of the child's welfare. That is to say, young patients have often been given an opportunity to consent to whatever medical treatment is offered to them but not to refuse it when it is recommended.

Increasingly, however, health professionals are unwilling to override what might be perceived as an unwise decision by a young person, particularly if the patient appears to have weighed up the arguments carefully or has prior experience of the particular treatment on offer. The BMA sees evidence of doctors increasingly doubting their authority to proceed where a young person refuses and looking to the courts for guidance. In practical terms, doctors are also often worried about ensuring willing compliance with after-care if the patient has been an unwilling recipient of treatment.

Life and death decisions

Extreme life and death choices are exceptional occurrences and are invariably challenging to any person. Nevertheless, a child or young person who has already experienced serious illness and various forms of medical treatment may be as well equipped as an older person to decide whether to agree to further similar treatment. Very hard choices arise when death is an inevitable consequence of the disease and treatment only offers a slender hope of prolonging life. Whatever their age, patients' own preferences should carry much weight in these circumstances. This is clearly not the same, however, as saying that society should accept unquestioningly a non-treatment decision by a child or young person whose medical condition appears amenable to successful treatment. Part of the difficulty with acknowledging that children and young people often have sufficient competence to make valid choices in important as well as trivial matters is that society generally wishes both to empower and to protect young people. These two aims can be incompatible and when they conflict, this creates particular dilemmas for health professionals.

Although confrontational situations clearly need to be avoided and, wherever possible agreement should be reached through dialogue and negotiation with young patients, this is not always possible. The courts are then brought in to arbitrate and ensure that decisions are made with transparency and due consideration of all pertinent factors. In respect of minors, the courts can be seen as representing societal moral priorities and appear to base judgements on a balancing of the risks of following the young person's apparent wishes against other risks, such as serious damage to health or death. Debate about this matter came to the fore in a 1999 legal judgement which sought to reconcile apparently incompatible societal aims: to follow a young person's expressed wishes, or save her life against her will.

M's refusal of a heart transplant

M was a 15-year-old who refused to consent to a heart transplant operation in 1999 when her own heart failed. Her mother gave legal consent on her behalf but health professionals were unwilling to proceed without M's agreement. M said that she did not want to die but neither did she wish to have the transplant since this would make her feel different to other people. " I understand what a heart transplant means, procedure explained... check-ups... tablets for the rest of your life. I feel depressed about that. I am only 15 and don't want to take tablets for the rest of my life ... I don't want to die. It's hard to take it all in. If I had children... I would not let them die. I don't want to die but I would rather die than have the transplant. I would feel different with someone else's heart - that is a good enough reason not to have a heart transplant, even if it saved my life." After listening to her views, Mr Justice Johnson decided that M was not capable of making the decision herself and he authorised the operation to go ahead despite her reluctance. "Events have overtaken her so swiftly that she has not been able to come to terms with her situation", he said. Once that decision had been made on her behalf, M agreed to comply with treatment.[8]

As in other similar cases, the judge emphasised that normally, the best interests of a child lay in respecting his or her integrity as a human being and supporting decisions made by the child on personal matters. Nevertheless, there might come a point where the powers which society invests in the legal system would be meaningless if there were no valid means of overriding a young person's decision to refuse lifesaving treatment. He recognised the risks of the patient carrying resentment for her whole life about the decision made on her behalf. He said that this risk, however, was impossible to assess accurately and had to be weighed against not just a risk but the certainty of her death, if action were not taken. In discussing the law and other legal precedents, however, the judge focussed on the moral arguments. He quoted Lord Balcombe in a previous case who maintained that:

> "Undoubtedly, the philosophy is that, as children approach the age of majority, they are increasingly able to take their own decisions concerning their medical treatment. In logic there can be no difference between an ability to consent to treatment and an ability to refuse treatment... Accordingly the older the child concerned the greater the weight the court should give to its wishes, certainly in the field of medical treatment. In a sense this is merely one aspect of the application of the test that *the welfare of the child is the paramount consideration*."

'The Welfare of the Child'

Where the child is too young and immature to make a valid decision, parents are the normal arbiters of where a child's best interests lie and how the child's welfare can be promoted. Society, however, is ready to intervene if parents appear to make unwise decisions for their children even though it would not stop parents making similar decisions for themselves. The moral justification is that society has special obligations to protect its most vulnerable members, among whom are children and young people.

The welfare of child C

C was almost five months old in September 1999 when the local authority applied to the court to allow a blood test to be taken to ascertain C's HIV status. Her parents were vehemently opposed to a blood test. C's mother had tested HIV positive in 1990 and again in 1998 but remained in good health and symptom-free. Both parents were very sceptical about the conventional medical approach to HIV. C's mother had, therefore, rejected medical advice about avoidance of mother-baby HIV transmission during pregnancy and labour. She refused a Caesarian section, opted to breast-feed and rejected the GP's advice that C should be tested and, if positive, be given prophylactic medication. The judge heard that C was at about 15% risk of infection during pregnancy and birth and that breast feeding increased the risk by between 5% and 10%. C's mother said she intended to breast feed until C reached the age of 18 months or 2 years. Medical experts advised that this increased the risks of transmission by 3% each year.

Mr Justice Wilson acknowledged the importance of parental views and said that these must feature into the overarching enquiry into C's welfare. He considered whether, in general, the united wishes of both parents should be perceived as correctly identifying a child's welfare and suggested this should be a rebuttable presumption. Nevertheless, he said that on the evidence provided in this instance, the parents' plans for protecting the child amounted to a 'hopeless programme'. He concluded that baby C had rights of her own which could not be subsumed within the rights of parents. The judge quoted various provisions of the UN Convention on the Rights of Child including the duty of the state to "ensure to the maximum extent possible the survival and development of the child" and "the right of the child to the enjoyment of the highest attainable standard of health". The court, therefore, ordered that testing take place.

This and some other examples of cases in which parental choice has been limited are discussed more fully in Chapter 2. The purpose of rehearsing some legal opinions in this chapter is to indicate how society's moral concerns can be reflected in such public proceedings.

3. Criteria for valid decision-making

In order for their decisions to carry moral weight, children and young people must be seen as capable of exercising judgement on the particular issue which requires a decision. Several fundamental criteria must be satisfied in order for any person to be deemed capable of decision-making. The criteria vary according to the decision to be made but basically require that person to have relevant information about all the options plus an appropriate level of understanding and experience. (See also Chapter 4). Clearly, choosing between several options which are likely to have roughly equivalent outcomes is less demanding than trying to weigh up the merits of options with vastly different consequences. It is also likely that competence to choose which school to attend or which examinations to take requires a child to have different skills to being able to decide about medical treatment.[9] Within medicine, profound variations exist in the gravity of the decisions to be made.

Children are clearly able to decide upon some aspects of treatment without necessarily being competent to determine every issue. To take a simple example, choosing between having an injection in one's left or right arm clearly requires a much lower level of understanding and experience than choosing not to have it all, since the latter choice may have serious consequences. In children, as in adults, competence can only be judged in relation to the particular decision which is at stake. It requires an awareness of the fact that choices have consequences and that different and specific implications arise from each choice. While perhaps complicated to describe, most people recognise what is involved in expressing preferences and feel able to do so on a range of issues from an early age.

A significant difference between children and adults, however, is that adults are presumed competent to make any decision, no matter how complex, until they prove otherwise. Their preferences, even if based on mere whim, tend to determine those matters which affect them. For children and young people the reverse is seen as the norm in that they are often perceived as incapable of forming reasoned views on any important issue. In our view, this anomaly needs to be addressed. Excluding babies and the very young, children and young people are generally competent to have a coherent view on a wide range of matters. Some of these matters, they can decide for themselves as long as they understand what the choice involves and its foreseeable implications. Clearly, they also need information about the consequences of the alternative options in a readily understandable form.

Theories relating to the decision-making abilities of children have in the past focussed on a rational model of decision-making. The view has been taken that an amount of cognitive complexity is required in order to weigh up options, and consider possible scenarios. Increasingly, however, it is realised that for all patients, decisions are based on far more than rationality. A range of factors, including intuition and emotion come into play when decisions are made. We support the suggestion that "a more realistic and respectful understanding of reason, instead of seeing it as clouded and distorted by emotion, is to see that feeling, memory and imagination can be sources of great insight"[10]. (See also Chapter 4).

Confronting difficult dilemmas

Particularly difficult human and ethical dilemmas arise when seriously ill people refuse potentially life-prolonging treatment or request interventions which health professionals do not think will genuinely improve their condition. The core purpose of medicine is to provide benefit for patients, whatever their age and circumstances. But assessing 'benefit' increasingly involves complex and conflicting arguments. As we have already made clear, having one's own values respected by other people is clearly a benefit and, in some circumstances, society values this above the benefit of keeping the person alive. Thus, adults are not given treatment against their wishes even though this would clearly save lives; the risks of forcibly inflicting treatment are recognised as so great as to make medical treatment a harm rather than a benefit.

Such dilemmas are greatly exacerbated when the patient is a child or young person. There is some evidence implying that health care decisions are approached differently for this population than for adult patients. Research indicates, for example, that health professionals tend to want to treat children and young people even in circumstances where they would not generally offer prolongation of treatment to an adult with the same condition. Doctors "frequently give young patients more chances to revive from and survive their illnesses than they offer to older, particularly elderly patients. Clinicians also seem more willing to impose greater burdens on children with fewer chances of success than on adults."[11] Part of this difference in attitude may be attributable to the fact that outcomes can be less predictable in children than in older patients but it also is indicative of health professionals wanting to give young people every chance of survival, even against the odds. The death of a child is universally seen as one of the most tragic experiences encountered but equally, there is a clear awareness that futile and invasive over-treatment must be avoided. Although we emphasise that disputes on life and death issues are exceptional, unfortunately they do occur and, in such cases, legal advice should be sought.

4. Involving minors in health care decisions

A fundamental ethical principle is that all patients who have some mental capacity, regardless of their age, should be properly informed in a way they can understand about medical matters that pertain to them. They must also have the opportunity to be involved as much as they are able and willing in all aspects of decision-making about their care and treatment. In cases where these principles are not followed, the onus must be on health professionals to demonstrate that either giving information would be inappropriate or that the patient does not want to make decisions.

Such justification could arise when individuals' level of understanding is demonstrably so extremely limited that it is impossible to discuss the issues with them. If there is evidence that it would be damaging to involve them in decision making or where patients are clearly reluctant to know the details, information should not be forced upon them. A key issue concerns the way in which health professionals assess an individual child's level of understanding and his or her ability to engage in meaningful dialogue about medical matters. At this point, it is sufficient to note that studies of young children's conversations make clear that pre-schoolers as young as 3 and 4 years of age can discuss issues and engage in decision-making.[12] Obviously, the ways in which they do so, and their capacity to deal with complex matters varies.

It can be argued that people learn how to make decisions by practice and by having the opportunity to exercise decision-making skills.[13] People learn by experience from their mistakes. Therefore, society needs to make allowance for children and young people to make some errors. Nevertheless, society requires there to be a safety net to ensure that the risks taken are confined within widely agreed parameters and therefore children's choices may be overridden when the risks of implementing them appear excessive.

5. When should children be protected from decision-taking?

A valid reason for withholding information or leaving people out of decision-making is that it would be harmful to them to do otherwise. In the past, it was usual for doctors to 'protect' adult patients from worry by withholding difficult information from them or by being misleadingly optimistic. Such paternalism is no longer acceptable. Medical ethics require that health professionals discuss diagnoses, prognoses and treatment options honestly with patients. If young people are deprived of essential facts to make an informed choice, the law is unlikely to judge them to be competent to make the decision (see Chapter 2). Opportunities for information sharing should be made available while recognising that there are valid individual differences in the extent to which patients wish to be involved in the detail. Above all, prevarication and deliberate misinformation must be avoided. Questions should be answered sensitively but honestly.

Thus, at least after the early preschool years, it is never acceptable for children to be excluded totally from participating in decision-making on matters of health care that concern them. The weight given to their views should properly be influenced by the level of their understanding. This does not necessarily mean that children, or even young adolescents, should be expected to be the final arbiter on a serious decision. They are used to turning to parents for advice and guidance and most young people continue to do so on serious matters through adolescence.[14]

Just as all patients have a moral right to be informed about aspects of their own health, they usually also have the opportunity to choose not to have detailed information. While valid decisions cannot be made without information, children or adult patients may want to exempt themselves from decision making that seems too difficult or emotionally painful and ask someone else to decide for them. Sometimes the decision not to be informed is a temporary one which gives the individual a breathing space to adjust. Therefore, information should always be on offer and patients be aware that they can change their minds and opt back into a decision-making role. Parents may also desire to protect children from bad news. Although health professionals need to pay attention to what families say about patients' sensitivity, feelings and wishes, nevertheless, the starting point has to be the right of all individuals to be properly informed and to be able to participate in decision-making as much as they are able to do so.

Shared decision-making is the preferred option in most instances. Perhaps the most obvious circumstance when it is particularly damaging to force (or expect) children to take the final decision is when one parent argues for one course and the other parent presses for the opposite. Inevitably, such decisions will be felt by the child as having an element of conflict over loyalty. Ordinarily, children are not, and should not, be expected to choose between their parents and such cases require sensitive management so that the child feels empowered to indicate his or her own preferences.

Summary

The BMA has set out some basic principles regarding the manner in which treatment of children and young people should be approached. These reflect standards of good practice, which find an echo in statute and international declarations.

a) Children and young people should be kept as fully informed as they wish and as is possible about their care and treatment. They also have a right to exempt themselves from some aspects of decision making although they should be encouraged to make their general preferences known.

b) The wishes and values of children and young people should always be sought and taken into account. The individual's overall welfare should be the paramount consideration and listening to minors' views is conducive to promoting their welfare in the widest sense.

c) The multi-faceted needs, including emotional needs, of children should be recognised.

d) Children and young people should be encouraged to make all those decisions which they feel comfortable and able to make. In the majority of cases, young people who have an understanding of what is involved can make responsible and reasoned decisions about medical treatment options.

e) Although minors should be treated in such a way as to promote their personal responsibility consistent with their needs, they should also be encouraged to take decisions in collaboration with other family members, especially parents, if this is feasible.

f) Wherever possible, decision making should not be hurried and patients given full opportunity to reflect, obtain more information and discuss the options in a supportive environment.

References

1. This is the convention adopted, for example, in the New Zealand Health Ministry's publication on *Consent in Child and Youth Health*, Wellington, 1998.

2. BPA, A Paediatrician's Brief guide to the UN Convention on the Rights of the Child, 1995.

3. The BMA has also published several reports focussing on the effects of poverty and deprivation on child health - add full refs.

4. This is articulated in international instruments such as the United Nations Convention on the Rights of the Child and national legislation, such as the Children Act.

5. See the discussion of 'Gillick' competence and confidentiality within the terms of the Frazier judgement in Chapter 2.

6. BMA draft tool kit on seeking consent, full refs to be added.

7. Alderson P. and Montgomery J. 1996.

8. Full refs to be added.

9. See BMA/Law Society, *Assessment of Mental Capacity*, BMA: London, 1996.

10. Alderson P. and Montgomery J. *Health Care Choices; Making decisions with children*, 1996.

11. Nelson LJ et al Foregoing medically provided nutrition and hydration in paediatric patients, J Law, Med and Ethics, 1995, 23: 33-46.

12. Dunn J. (1988) *The Beginnings of Social Understanding*. Oxford: Blackwell.

13. Ref to be added.

14. Rutter M. (1979) *Changing Youth in a Changing Society: Patterns of adolescent development and disorder*. London : Nuffield Provincial Hospitals Trust (1980), Cambridge, Mass: Harvard University Press; Rutter M. and Rutter M. *Developing Minds: Challenge and continuity across the lifespan*. Harmondsworth, Middx: Penguin; New York: Basic Books, 1993.

Chapter 2: The Legal Framework for Consent

Ethical, clinical and legal imperatives underpin seeking consent in medical practice. The previous chapter has addressed some aspects of these. The purpose of this chapter is to outline the legal issues and boundaries important in obtaining consent for children's health care. The chapter covers the law in England, Wales and Northern Ireland. The law is substantially the same in these jurisdictions, and where there are differences these have been noted. The law in Scotland, on the other hand, differs greatly, and for this reason will be addressed by the BMA separately.

Common, or judge-made, law is a major influence on medical practice involving children. The cases which go to court tend to be extreme, where the treatment in question is non-therapeutic, or where the parties to the decision have been unable to reach agreement. Seeking agreement amongst those involved in the child's care, which can include any number of the patient, parents, carers, a local authority and the courts is a reality in clinical practice, although the law, in principle, always identifies one or more persons, or ultimately a court, whose view will prevail. Although it attempts to reflect the practical reality, for example by emphasising the importance of the child patient's welfare and views, case law usually develops around one party (the court) being offered a choice of whether to accept or reject treatment. How to balance this ability to rely on the acceptance of treatment by just one of the legally entitled parties with the moral imperative to discuss, consult and reach agreement is the focus of this book.

Furthermore, judges are usually more concerned to resolve the particular dispute than to provide detailed guidance for future cases, although they do explain the reasoning behind the decision. It is debatable whether law based on these hard cases provides a helpful framework for doctors in everyday practice. Certainly the examples given in this chapter are unlikely to be those most health professionals face. But the decisions reached do identify, which does not always mean clarify, what is lawful and what is not. In this complex area of law the reasoning can be as important as the decision.[1]

2.1 Circumstances which permit treatment

In medical practice, it is usually the patient's consent which indicates that a doctor may proceed with treatment. Valid consent legitimises what would otherwise be unlawful conduct; the merest touching of an individual without consent can attract responsibility at law. Consent from just one legally competent source is sufficient to allow treatment to proceed. Where consent is unavailable, for example in an emergency and the patient is unable to communicate wishes, or, in the case of children, where nobody with parental responsibility is available, it is lawful for doctors to proceed with treatment necessary to preserve the life, health or well being of the patient.[2]

Additionally in caring for children, it is also assumed to be acceptable, a view which the BMA shares, to administer life-saving treatment against the wishes of a child or his or her parents if the situation is an emergency and any delay would lead to serious harm or even the death of the child. If time permits, however, attempts at resolution and ultimately the involvement of the courts are preferable to overriding the family's wishes.[3] Mechanisms for resolution and when the involvement of the courts might be appropriate are discussed below and throughout this book.

2.2 Consent

In the care of children, consent for treatment to proceed can come from any one of a number of sources; a competent young person, parents (and in some circumstances other carers) or the courts. The ability of each to give consent runs concurrently, and is not wholly extinguished until the young person reaches 18.[4]

2.2.1 Competent young people

The age of majority is reached at 18. No third party is entitled to give consent to treatment on behalf of an individual who has attained that age.[5] Additionally, the Family Law Reform Act 1969 provided for a presumption of competence to consent to treatment at age 16.

> *The consent of a minor who has attained the age of sixteen years to any surgical, medical or dental treatment which, in the absence of consent would constitute a trespass to his person, shall be as effective as it would be if he were of full age; and where a minor has by virtue of this section given an effective consent to any treatment it shall not be necessary to obtain any consent from his parent or guardian.*[6]

The Act defines 'surgical, medical or dental treatment', as including 'any procedure undertaken for the purposes of diagnosis, and ... any procedure (including, in particular, the administration of an anaesthetic) which is ancillary to treatment as it applies to that treatment'.[7] The definition is assumed to include preventive measures intended to benefit health, for example immunisation. It is unlikely to extend, however, to tissue donation, cosmetic surgery or research.[8]

The Family Law Reform Act also provides that:

> *Nothing in this section shall be construed as making ineffective any consent which would have been effective if this section had not been enacted.*[9]

The effect of this provision, in place presumably to allow for consent to be given where the young person lacks capacity, or has the capacity to consent to some aspects of care but not others, is discussed below.

The statutory provision in Northern Ireland is the same.[10]

Case Law

Case law has explored the ability of people under 16 to give consent. In a case brought by Victoria Gillick in the early 1980s, for the first time the courts were asked to describe the parental 'right' to consent for their children.[11]

Mrs Gillick took her local health authority to court over its refusal to give an assurance that her five daughters would not be given contraceptive advice and treatment without her knowledge and consent whilst under 16 years old. The case followed the publication of a Department of Health and Social Security circular which advised that a doctor consulted at a family planning clinic by a girl under 16 would not be acting unlawfully if he prescribed contraceptives for her provided that he acted in good faith and to protect her against the harmful effects of sexual intercourse. In seeking a declaration that this advice was unlawful, Mrs Gillick argued that the girl's consent would be legally ineffective and inconsistent with parental rights. It was therefore necessary to involve parents in such decisions.

Although this argument was accepted by the Court of Appeal, it was rejected by the majority in the House of Lords. The majority opinion there was that the relevant test was whether the girl had reached an age where she had 'sufficient understanding and intelligence to enable her to understand fully what was proposed'.[12] If she had, the doctor would not be acting unlawfully in providing advice and treatment.

In reaching this decision, it was also held that 'parental rights were recognised by the law only as long as they were needed for the protection of the child and such rights yielded to the child's right to make his own decisions when he reached a sufficient understanding and intelligence to be capable of making up his own mind. Accordingly, a girl under 16 did not, merely by reason of her age, lack legal capacity to consent to contraceptive advice by a doctor'.[13] Indeed, Lord Fraser suggested that it seemed to him to be 'verging on the absurd to suggest that a boy or girl aged 15 could not effectively consent, for example, to have a medical examination of some trivial injury to his body or even to have a broken arm set'.[14]

Gillick v West Norfolk and Wisbech Area Health Authority and another

This judgment firmly rejects the previously held notion that anybody under the age of 16 was not able to consent to medical treatment due to insufficient maturity. Where a competent young person consents to proposed treatment, it is not necessary to have parental consent in addition to that of the young person. Indeed, treatment may proceed against the wishes of the parents or without their knowledge.[15]

It is widely accepted that the judgment also implied that a competent child is owed the same duty of confidentiality as any adult patient. This view is reflected in the guidance of professional and regulatory bodies which make no distinction between adult and child patients when discussing the existence of an obligation of confidentiality.[16] Confidentiality is discussed further in chapter 3.

The standard of competence set in the *Gillick* case is still important today. The courts have since given further guidance on capacity which is discussed in chapter 4. Chapter 4 also addresses how to assess competence to consent.

2.2.2 Parents and carers

A child's biological parents are the child's legal parents, unless the child has been adopted or was born as the result of donor insemination or other methods of assisted reproduction. Where the child has been adopted by a single person or married couple, the adopters are the child's legal parents. Where the child has been born as a result of assisted reproduction, there are provisions in the Human Fertilisation and Embryology Act 1990 which determine the child's parentage.

Any person who has parental responsibility for a child may, in law, consent to treatment on that child's behalf. Not all parents will have parental responsibility. Legally both parents have parental responsibility if they were married at the time of the child's conception, or birth, or at some time after the child's birth. Neither parent loses parental responsibility if they divorce.

If the parents have never married, only the mother automatically has parental responsibility but the father may acquire that status by a parental responsibility order, agreed with the mother, or by the authority of a court.[17] People other than the parents may also acquire parental responsibility by the appointment of a guardian or on the order of a court. For example, a local authority acquires parental responsibility when the child is the subject of a care order and this endures for the period of the order. Other people can acquire parental responsibility by a residence order.

Parents do not have an unlimited right to authorise or refuse treatment, and the limits of parental choice are discussed in section 2.3.

In addition to people with parental responsibility, any person who has care of a child may do 'what is reasonable in all the circumstances of the case for the purpose of safeguarding or promoting the child's welfare'.[18] This includes the power to consent to medical treatment.[19]

2.2.3 The courts

Court involvement is necessary in only a minority of cases, and the BMA is keen to see the use of the courts minimised as a result of effective shared decision-making and the achievement of agreement between those involved in the decision. The courts themselves have said that whilst good communication is important, where there is a clear dispute the matter should be brought to a court for resolution as quickly as possible.[20] It will usually be the case that agreement can be reached between the young person, if able to participate in decision-making, those with parental responsibility and the health care team. Their goal is the same - to benefit the patient - and in the vast majority of cases it will be possible to agree on a route to achieve this. In such cases, the BMA does not see a need for the involvement of the courts.

If, however, agreement cannot be reached in a reasonable time period, which will depend on the nature and likely course of the patient's condition, it may be necessary to seek legal review and ask the courts to intervene in the determination of best interests.

Where the courts do become involved, there are a number of mechanisms which can be invoked, the principal ones of which are described briefly below. The courts are available at all hours should a matter requiring urgent attention arise. The High Court is the appropriate court for medical treatment decisions. Outside normal office hours, contact should be made, normally by counsel, with the security officer at the Royal Courts of Justice in London (telephone 020 7936 6000). He or she would contact the designated urgent business officer by telephone whose responsibility it would be to assess the urgency of the application and, if appropriate, to contact the Duty Judge. The Judge would, if necessary, contact the Official Solicitor. The Judge may deal with the matter over the telephone, or may direct attendance at his or her lodgings. It is prudent to have a medical expert available to speak to the Judge in such circumstances.

An overarching consideration when a court determines any matter relating to the upbringing of a child is the requirement of the Children Act that the child's welfare must be the paramount consideration. This is true whether the court is exercising a power under the Children Act or exercising its inherent jurisdiction (see below).

Some guidance on what factors are relevant to the consideration of welfare is given in the Children Act:

> *(a)* *the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding);*
> *(b)* *his physical, emotional and educational needs;*
> *(c)* *the likely effect on him of any change in his circumstances;*
> *(d)* *his age, sex, background and any characteristics of his which the court considers relevant;*
> *(e)* *any harm which he has suffered or is at risk of suffering;*
> *(f)* *how capable each of his parents, and any other person in relation to whom the court considers the question to be relevant, is of meeting his needs.*[21]

The same guidance is given in the Children (NI) Order 1995.

The Children Act may be used to authorise or prohibit steps in relation to medical treatment. It does this through the power of the court to make 'specific issue' and 'prohibited steps' orders.

A specific issue order is defined as:

> *an order giving directions for the purpose of determining a specific question which has arisen, or which may arise, in connection with any aspect of parental responsibility for a child*[22]

Its purpose is to resolve a situation in which there is disagreement over the exercise of parental responsibility.

Complementing this, a prohibited steps order is:

> *an order that no step which could be taken by a parent in meeting his parental responsibility for a child, and which is of a kind specified in the order, shall be taken by any person without the consent of the court*[23]

This has the effect of preventing the exercise of parental responsibility in a particular way without the consent of the courts.

In addition to specific legislation giving the courts powers, the courts also have ancient, non-statutory (inherent) jurisdiction over children. This jurisdiction has been described as 'theoretically unlimited'[24] and means the courts have the power, amongst other things, to authorise treatment (consent) or forbid a course of action dependent upon the child's best interests. It is a procedure which involves the collation of all the evidence, with the court ultimately determining what is in the best interests of the minor.

The wardship jurisdiction is broad, and embraces things which parents do not have the power to do.[25] It also includes power to make orders to require third parties to act in a particular way. For example, a doctor may be authorised to or forbidden from carrying out proposed treatment of the ward, although the courts will not order a doctor to provide treatment which is contrary to his or her clinical judgment (see section 2.5). Similarly it may prevent the media from revealing the identity of a child. The court is entitled to override the wishes of any other person in relation to the ward, including the child him or herself.

In contrast, the courts have no power to consent treatment medical treatment for or on behalf of an incapacitated adult. In such cases, the courts may only declare whether proposed medical treatment for an incapacitated adult is lawful as being in the patient's best interests.[26]

It is now usual for applications in relation to the medical treatment of children to be made within the inherent jurisdiction of the high court.[27] An interested party may make a child a ward of court by issuing a summons. This could, for example, be a health professional involved in the child's care. Once a summons has been issued, the child immediately is in the care of the court and no important steps may be taken without the court's permission. This endures for 21 days after which time it will lapse unless an application is made to the court for a decision on its continuation.

The inherent jurisdiction of courts in relation to children is limited by the Children Act, such that it cannot, for example, be used to place a child in care. The Children Act also restricts the use of the inherent jurisdiction by a local authority to those cases where the result could not be achieved by another means (making an order of any kind) and where significant harm would arise to the child if wardship powers were not exercised. A health authority does not fall within the Act's definition of local authority.[28]

2.3 Limits on decision making: Parents

People with parental responsibility for babies and young children have the legal power to give or withhold consent to treatment, provided that they are not acting contrary to the child's best interests and are acting on the basis of accurate information. It will not always be clear whether the likely medical benefits of treatment outweigh its burdens, and in such cases parents are usually best placed and equipped to weigh the medical advice and apply it to their child's circumstances. Parent's powers to determine whether a treatment goes ahead are, however, are subject to limitations. For example, a court would be likely to override the refusal of parents if the proposed treatment would provide a clear benefit to the child or if the statistical chances of recovery are good. Similarly, a court is unlikely to uphold requests for treatment where the medical evidence shows that continued treatment is not in the child's best clinical interests.

Section 2.5 looks at circumstances in which the courts should be involved in decisions. The BMA believes it is right that there are things which parents cannot consent to, to ensure that an independent decision is made in accordance with the child's best interests. For example, the safeguard of review by a court should be invoked where there is disagreement over decisions to withdraw or withhold life-prolonging treatment.

C was a 16 month old girl suffering from spinal muscular atrophy type 1, a progressive disease which causes severe emaciation and disability.[29] She was dependent on intermittent positive pressure ventilation. Her doctors sought authority from the Family Division of the High Court to withdraw the ventilation, and to not reinstate it or resuscitate C if she suffered further respiratory relapse. They maintained that further treatment would cause her increasing distress, could cause medical complications, and could do little more than delay death without significant alleviation of suffering.

The judge described the parents as highly responsible orthodox Jews, who loved their daughter but who were unable to 'bring themselves to face the inevitable future'. The doctor's treatment plan of withholding resuscitation and ventilation and providing palliative care was endorsed by the judge to 'ease the suffering of this little girl to allow her life to end peacefully'.

Re C (Medical treatment)

There has been one reported case in which the courts upheld parents' refusal to accept the health team's recommendation.[30]

C suffered from biliary atresia, a liver defect, and was not expected to live beyond two and a half years without a liver transplant. He had had major invasive and unsuccessful surgery at three and a half weeks old, which had appeared to cause him severe pain and distress. His mother did not want to expose her son to further distress and believed that it would be best for him to be cared for by her abroad, where C's father was working. C was referred to a hospital carrying out liver transplants, but when an organ became available, C and his mother were abroad and unable to be contacted. When they returned to England, the mother continued to oppose the operation.

The local authority asked the court to exercise its inherent jurisdiction to order (1) that a transplant would be in C's best interests; (2) giving permission to perform the surgery; and (3) for the child to be returned to England for the surgery. The court of appeal held that it was not in C's best interests to return to this country to undergo the operation.

Re T (A minor) (Wardship: medical treatment)

In deciding the case, Lord Justice Waite made the point, which the BMA endorses, that:

> *the greater the scope for genuine debate between one view and another [about the best interests of the child], the stronger will be the inclination of the Court to be influenced by a reflection that in the last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of its life will be taken for it by the parent to whom its care has been entrusted by nature.*

This decision makes clear the importance and impact of a broad understanding of best interests. It illustrates the validity and weight the courts have given to parents' assessment of their children's best interests and how the broad effects on the family can be a factor in these interests. The decision is not uncontroversial, however. Although courts are generally deferential to parental wishes, in this case the court was especially so. It is difficult to know how much the court was influenced by the practical difficulties of ensuring compliance with the proposed order because the parents were abroad, and by the fact that the parents were health professionals. It is not clear, therefore, whether this precedent would be followed in cases which did not share such particular circumstances. In the event, C was later to have a liver transplant with his mother's consent.

In another case, the Family Division of the High Court overrode a mother's refusal to allow her baby to be tested for HIV.[31]

C was five months old when a case was brought by her local authority for a specific issue order to allow her to be subjected to a blood test with a view to determining whether she was infected with HIV. The child's mother had known she was infected with HIV at the time of C's delivery vaginally. The mother continued to breast feed her baby, despite medical advice about the risks of transmission of infection. Her GP recommended HIV testing to establish whether C was infected, and based on that information, to plan for C's management and care.

The parents, who favoured complementary therapies and objected to any conventional therapy, contended that it had not been established that HIV was truly a virus, nor that it was the sole cause of AIDS. They also dismissed the possibility of transmission of the infection to C by breast feeding.

The court held that testing would clearly be in C's best interests, and that overall the advantage of the proposed test was very substantial and the case for testing overwhelming.

An appeal was not allowed.

Re C (A child)

The judges in this case referred back to the suggestion in *Re T* (above) that there was a rebuttable presumption that the united appraisal of both parents would be correct in identifying where the welfare of the child lay, and that support for that proposition could be derived from the Children Act[32] and the European Convention on Human Rights.[33] Accordingly, a court invited to override the wishes of parents must do so extremely cautiously, although circumstances clearly arose in which this was the appropriate course of action.

2.4 Limits on decision making: Young people

At the time, the *Gillick* decision was regarded as a watershed: it appeared to clarify the issues around young people's consent to medical treatment, giving them independent legal capacity to act autonomously in decisions about their health care when capable of doing so. In a 1990 publication, for example, the author commented that 'as a result of this decision it seems that, provided the 'maturity test' is satisfied, parents can neither compel nor prevent medical treatment'.[34] A right to refuse seemed to most a logical extension of a right to consent. The law appeared to be dealing with competent young people as it would with adults. In subsequent cases regarding refusal, however, this has not been borne out.

The first reported time the rights of a mature, competent in accordance with the standards set in *Gillick*, minor were tested with respect to medical treatment was in 1991.[35]

R was a 15 year old girl who refused anti-psychotic treatment. She had poor and sometimes violent relationships with her parents and appeared to experience visual and auditory hallucinations and sometimes suicidal thoughts. But she also experienced periods of lucidity, brought about by drug therapy. During these intervals her doctors believed that she did have the necessary competence to make decisions about her treatment. The local authority initiated wardship proceedings with the intention of seeking authority to provide anti-psychotic treatment whether or not R consented.

The court of appeal did authorise treatment to proceed, even against her wishes. R was held to lack the necessary competence to make the decision.

Re R (A minor)

A significant aspect of this case was its description of parental powers. Lord Donaldson said:

> *[A Gillick competent] child can consent, but if he or she declines to do so or refuses, consent can be given by someone else who has parental rights or responsibilities. The failure or refusal of the Gillick competent child is a very important factor in the doctor's decision whether or not to treat,*

> *but does not prevent the necessary consent being obtained from another competent source.*[36]

In other words, any valid consent enables treatment to be given lawfully. Thus the rights of parents and others are not extinguished when a young person attains the capacity to consent on his or her own behalf.

A year later, the position of a young person who was presumed to be competent by virtue of s8(1) of the Family Law Reform Act 1969 was considered by the Court of Appeal.[37]

W was 16 years old and living in a specialist adolescent residential unit under local authority care. Her physical condition due to anorexia nervosa deteriorated to the extent that the authority wished to transfer her to a specialist hospital for treatment. W refused, wishing instead to stay where she was and to cure herself when she decided it was right to do so. She appeared capable of understanding the information given to her and what would be the consequence of not accepting the proposed treatment regime. Her refusal was, however, overridden with the argument that it was symptomatic of her condition which involved a desire not to be treated.

Re W (A minor) (Medical treatment)

Again, the basis of the decision itself was that the young person was not in fact competent to refuse treatment. However, the court was strongly of the view that even if she was competent to refuse, treatment would have been authorised to proceed because it was in her best interests. In this case that Lord Donaldson used a different analogy:

> *I now prefer the analogy of the legal 'flak jacket' which protects the doctor from claims by the litigious whether he acquires it from his patient, who may be a minor over the age of 16 or a 'Gillick competent' child under that age, or from another person having parental responsibilities which include a right to consent to treatment of the minor. Anyone who gives him a flak jacket (ie consent) may take it back, but the doctor only needs one and so long as he continues to have one he has the legal right to proceed.*[38]

In other words, a refusal of treatment by a young person up to the age of 18, even if that person is competent, can be overridden if consent is given by a parent or a court, provided that the treatment is in the young person's best interests. These comments, and those in *Re R* (see above) were not the subject of matters which fell to be decided by the court, although are likely to influence strongly any future decisions if there were to be a case in which a young person was found to be competent to refuse treatment.

Whilst the courts have indicated a willingness to impose treatment regardless of a young person's capacity, the ability of parents to approve treatment without court involvement is more controversial. The judges in *Re W* emphasised that it was important to go to court before imposing invasive treatment upon a child who refuses and who might be competent.

2.4.1 A statutory right to refuse

The Children Act gives a competent young person the right to refuse to submit to medical or psychiatric examination or other assessment which has been directed by the court for the purpose of an interim care, supervision or emergency protection order, provided that the child 'is of sufficient understanding to make an informed decision'.[39] This was tested in the case of *South Glamorgan County Council v B and W*, where it was held that the inherent jurisdiction can be used to override a child's statutory right to refuse examination and treatment.[40] Since the application to the Family Division of the High Court in this case was by a local authority, the power to use the inherent jurisdiction depended on showing that the child was likely to suffer significant harm.

South Glamorgan County Council v B and W was concerned with a 15 year old girl, A, who had long standing behavioural problems. She had confined herself to the front room of her father's house with the curtains drawn for approximately 11 months, and was described as indulging in obsessive behaviour and being demanding and domineering towards her father and aunt who cared for her. The local authority commenced care proceedings, and a care order was made with a direction for her to receive psychiatric examination and assessment under s38(6) of the Children Act. A refused to consent to this, and the local authority brought proceedings to ask the court to exercise its inherent jurisdiction to override A's refusal.

Despite finding her competent, the judge ruled that there was power under the inherent jurisdiction to override the refusal of a person under 18 years of age to submit to psychiatric assessment and examination, even where the Children Act made specific provision that the refusal of a competent young person should be respected.

South Glamorgan County Council v B and W

The court held that

> *The High Court exercising its inherent jurisdiction could override the wishes of a girl of 15 years even if she was capable of sufficient understanding to make an informed decision about proposed medical treatment. The courts' jurisdiction over minors was unlimited and had not been abrogated by the Children Act 1989.*[41]

Commentators have criticised this decision, with Kennedy and Grubb, for example, stating that 'it is not easy to reconcile this view of the law with the principle that prerogative power yields to inconsistent statutory provisions'.[42] It is arguably less respectful to override a young person's rights on grounds of age rather than of competence to make the decision.

2.4.2 Advance refusals

Since their refusals of treatment may not determine their care, the advance refusals (directives) of young people will not carry the same weight as the advance refusals of competent adults. However, as with any expression of wishes, advance refusals are important in decision-making and assessment of best interests.

2.4.3 Summary and comment

The state of the law is the subject of much academic debate, and can be confusing for practitioners. Common sense might demand that a right to consent carries with it a corresponding right to refuse. Kennedy, for example, described the decision in *Re R* as 'driving a coach and horses through *Gillick*'.[43] It also appears that the courts have adopted a strict test in determining necessary competence which even patients for whom competence is assumed (those over 16) are unlikely to satisfy.[44] Thus it has been argued that 'judges should not go through the pretence of applying a functional test of capacity ... [and that the] ... law should openly declare that welfare reigns when grave decisions with momentous outcomes are considered and recognise that adolescent autonomy is, inevitably, circumscribed'.[45]

But it is similarly arguable that there is a justifiable practical distinction between consent and refusal. When consenting, the patient is accepting the advice of a qualified professional. Refusal is a rejection of the advice of an expert from a necessarily less well informed position. It may have grave consequences in terms of closing down options for future treatment.[46] Thus other commentators have described the decisions as simply interpreting the effect of s8(3) of the Family Law Reform Act which preserves the right of others to consent.[47]

> *Adolescence is a period of progressive transition from childhood to adulthood and as experience of life is acquired and intelligence and understanding grow, so will the scope of the decision-making which should be left to the minor, for it is only by making decisions and experiencing the consequences that decision-making skills will be acquired ... good parenting involves giving minors as much rope as they can handle without an unacceptable risk that they will hang themselves.*[48]

The BMA's view is that there is a need for clarity about when it is acceptable to override a young person's wishes and when it is not. The Association would not wish to see young people's wishes overridden lightly nor without any opportunity for those wishes to be heard and given due consideration. The Association places a great deal of importance on the views of young people, and has stated elsewhere that 'minors who are clearly competent to agree to treatment must be acknowledged as also having an option to refuse treatment if they understand the implications of so doing'.[49] It is accepted, however, that there is some practical distinction between consent and refusal, and that the level of competence necessary to refuse treatment which may prolong or significantly enhance life is very high. It is also accepted that in some cases even a competent refusal may not be determinative.

The concurrent rights of parents raise questions over disclosure of information. Confidentiality is discussed in more detail in chapter 3, although it is worth noting here that the general rules of confidentiality are the same for all patients, and that confidentiality should only be breached where there is an overwhelming public interest. Where young people refuse essential treatment and also refuse to allow disclosure to their parents, doctors will have to consider whether there are sufficient grounds to justify a breach of confidentiality. In such cases, the child should be informed of the decision in advance.

2.5 When to go to court

There is no simple answer to the question of when the courts should be involved, and it is not possible, or even desirable, to attempt to draw up a definitive list of circumstances in which the courts should be involved. It is possible to give some general guidance, however, and to note circumstances where the law has been clear that decisions of a particular type require court review.

In general terms, the independent review of a court to assess what is in a particular child's best interests is appropriate where;

- agreement over how to proceed cannot be reached (for example where consent is refused by the holders of parental responsibility);
- the proposed care is beyond the scope of parental consent (because it is controversial or non-therapeutic or the people with parental responsibility lack the capacity to take the decision);
- it is not clear whether a course of action is lawful (for example where a seemingly competent young person refuses treatment);
- it is not clear whether the people with parental responsibility are acting in the best interests of the child;
- the courts require it;
- the child is a ward of court;
- the administration of treatment requires the use of force on a competent young person; or
- the treatment requires detention outwith the provisions of the Mental Health Act.

The role of the court is to declare whether a proposed course of action is lawful, and to do so with regard to the best interests of the child in question. The courts do not have the power to require a doctor to treat:

> *No doctor can be required to treat a child, whether by the court or in the exercise of its wardship jurisdiction, by the parents, by the child or anyone else. The decision whether to treat is dependent upon an exercise of clinical judgment, subject only to the threshold requirement that, save in exceptional cases usually of emergency, he has the consent of someone who has the authority to give that consent.*[50]

Thus, whilst the authorisation of a court tells doctors that treatment is lawful, it does not mean that treatment will definitely go ahead.

As has been described above, the court is required to have as its paramount consideration the welfare of the child. Going to court can be distressing for those concerned and it is essential that ongoing support is provided for the child, parents, other relatives and carers and the health care team. In general, the BMA believes that less confrontational means of problem solving are preferable. It also acknowledges, however, the great benefits of a legal system which can give rulings very quickly where necessary, and believes that this is an important safeguard both for young people and for their carers.

Concerns have been expressed over the ethical and clinical implications of court decisions which have shown it to be lawful to proceed with treatment against the wishes of even competent young people where consent from a parent is forthcoming.

This was one of the issues under consideration in a family division case involving the treatment of young people in a hospital adolescent unit (see also chapter on mental health).[51]

Three young people, K, W and H were patients in a hospital's secure adolescent unit. The parents of all three had given their consent to treatment. The hospital authority applied to the high court for orders under the Children Act, in keeping with its policy of doing so where there was doubt about a child patient's ability to consent.

Referring back to the judgment in *Re R*, Thorpe J refused the application as 'misconceived and unnecessary' since the hospital was lawfully entitled to proceed with treatment based with the authority of parental consent. This was held to be the case even if the young people themselves refused the treatment.

Re K, W and H (Minors) (Medical treatment)

The BMA would be concerned to see the use of the courts restricted to those cases where consent is not available from another source, a situation which would appear contrary to the recommendation of the judges in *Re W*[52] that the courts' view should be sought before imposing treatment upon a child who may be competent (see above). Although involving the courts is usually done at the end of a process of attempting to reach consensus, it provides an important forum for the exploration of a young person's welfare. The BMA advises doctors to consider whether there is benefit in bringing cases to the courts where there is doubt over the best course of action. Doctors should approach their lawyers for advice on this issue.

2.6 Summary

An effect of the legal developments has been to create a stark distinction between adult and child patients. Nobody under 18 appears to enjoy the right to determine whether or not to accept a treatment which is offered. Indeed, no one person has an overall right to determine treatment (although in specific circumstances this will be the effect). Refusal by any party does not override the legal protection afforded to a doctor who proceeds with consent from a competent young person, somebody with parental responsibility or the court.

To summarise the legal position, therefore:

A doctor may provide treatment for a person under 18 provided that there is valid consent from at least one of:

- a competent child;
- a person or local authority with parental responsibility; or
- a court.

With such a consent, a doctor will be protected from a charge of battery, even if one of more of the above refuse consent. It does not, however, exclude liability for negligence. Furthermore, just because consent has been given by someone does not mean that it is necessarily in the child's best interests for the treatment to be given. The doctor has legal and ethical obligations over and above the requirement to obtain valid consent.

1. Kennedy I. *Treat me right*. Oxford: Oxford University Press, 1988, pp118.

2. *Re F* [1990] 2 AC 1; sub nom *F v West Berkshire Health Authority* [1989] 2 AER 545.

3. Two cases involving Jehovah's Witness children have suggested that the approval of a court should be sought before the administration of treatment. *Re O* [1993] 2 FLR 149; *Re S* [1993] 1 FLR 376.

4. *Re W (a minor) (medical treatment)* [1992] 4 All ER 649.

5. Since the early 1980s, the UK Government has been considering reform of the law to allow the appointment of health care proxies who would be lawfully entitled to take decisions about health care. At the time of writing, these proposals continued to be under discussion. Information about developments in this area can be obtained from the BMA's Medical Ethics Department and on the BMA web page (www.bma.org.uk).

6. Family Law Reform Act 1969 s8(1).

7. Family Law Reform Act 1969 s8(2).

8. Montgomery J. *Health care law*. Oxford: Oxford University Press, 1997: 283.

9. Family Law Reform Act 1969 s8(3).

10. Age of Majority Act (NI) 1969 {get ref}.

11. *Gillick v West Norfolk and Wisbech Area Health Authority and another* [1985] 3 All ER 402.

12. *Gillick v West Norfolk and Wisbech Area Health Authority and another* [1985] 3 All ER 402:403.

13. *Gillick v West Norfolk and Wisbech Area Health Authority and another* [1985] 3 All ER 402:403.

14. *Gillick v West Norfolk and Wisbech Area Health Authority and another* [1985] 3 All ER 402:409.

15. *Gillick v West Norfolk and Wisbech Area Health Authority and another* [1985] 3 All ER 402:?.

16. General Medical Council. *Confidentiality*. October 1995, London: GMC.

17. The government has announced its intention to amend these rules, following a consultation exercise carried out in 1998 by the Lord Chancellor's Department, so that parental responsibility is automatically conferred on unmarried fathers whose names appear on their child's birth certificate; this would require a change in legislation and it has not been established when these changes will take place.

18. Children Act 1989 s3(5).

19. *B v B* [1992] 2 FLR 327. {Get Ref}

20. *Re MB (Medical treatment)* [1997] 2 FLR 426, [1997] Fam Law 542, FD.

21. Children Act 1989 s1(3).

22. Children Act, op cit: s8(1). {Get Ref}

23. Children Act, op cit: s8(1). {Get Ref}

24. *South Glamorgan County Council v B and W*, op cit: 163.

25. *Re R (A minor) (Wardship: Medical treatment)* [1991] 4 All ER 177.

26. For further discussion of adult and child patients, see Harper R S. *Medical treatment and the law: The protection of adults and minors in the Family Division*, Bristol: Family Law, 1999: Ch 4.

27. *Re Z (A minor) (Identification: Restrictions on publication)* [1997] Fam 1. {Get ref}

28. Children Act, op cit: s105(1). {Get Ref}

29. *Re C (Medical treatment)* [1998] 1 FLR 384.

30. *Re T (A minor) (Wardship: medical treatment)*; sub nom *Re C (A minor) (Parents' consent to surgery)* [1997] 1 All ER 906.

31. *Camden London Borough Council (Applicant) v (1) A (2) B (3) C (by her guardian at litem) (respondents)*; sub nom *Re C (A child)* (1999), and Birmingham Post: *HIV mother fails to stop baby's blood test*. 22 September 1999.

32. Children Act, op cit: s1(5).

33. *European convention on the protection of human rights and fundamental freedoms*, 1950.

34. Eekelaar J, Dingwell R. *The reform of child care law: A practical guide to the Children Act 1989*. London: Routledge, 1990, pp24.

35. *Re R (a minor) (wardship: medical treatment)* [1991] 4 All ER 177. {Get Ref}

36. *Re R (a minor) (wardship: medical treatment)* [1991] 4 All ER 177: ?. {Get Ref}

37. *Re W (a minor) (medical treatment)*, op cit.

38. *Re W (a minor) (medical treatment)*, 657 op cit.

39. Children Act 1989 s38(6).

40. *South Glamorgan County Council v B and W* [1993] 11 BMLR 162.

41. *South Glamorgan County Council v B and W* [1993] 11 BMLR 162: 163.

42. Kennedy I, Grubb A eds. *Principles of medical law*. New York: Oxford University Press, 1998, pp209.

43. Kennedy I. Consent to treatment: The capable person. In: Dyer C (ed) *Doctors, patients and the law*. {publisher}, 1992, pp.

44. Elliston S. If you know what's good for you: Refusal of consent to medical treatment by children. In: McLean SAM, editor. *Contemporary issues in law, medicine and ethics*. Aldershot: Dartmouth, 1996.

45. Bridge C. Religious beliefs and teenage refusal of medical treatment, op cit: 594.

46. Mason J K, McCall Smith R A, *Law and medical ethics*. ?: Butterworths, 1994, pp229.

47. Mason J K, McCall Smith R A, *Law and medical ethics*. ?: Butterworths, 1994, pp227-228.

48. Lord Donaldson {Get Ref}

49. British Medical Association. Medical ethics today: Its practice and philosophy, London; BMA, 1993: 85.

50. *Re R (a minor) (wardship: medical treatment)*, op cit: ?.

51. *Re K, W and H (Minors) (Medical treatment)* 15 BMLR 60: 60.

52. *Re W (a minor) (medical treatment)* [1992] 4 All ER 649: 657. {Get Ref to check page nos}

Chapter 3: Confidentiality and young people

1 Patients' rights to confidentiality

All patients are entitled to expect that information about themselves will not be disclosed to other parties without their knowledge and consent. Regarding the general duty of confidentiality owed to all patients, the General Medical Council states[1]:

"Patients have a right to expect that you will not disclose any personal information which you learn during the course of your professional duties, unless they give permission. Without assurances about confidentiality patients may be reluctant to give doctors the information they need in order to provide good care...When patients give consent to disclosure of information about them, you must make sure they understand what will be disclosed, the reasons for disclosure and the likely consequences...You must respect requests by patients that information should not be disclosed to third parties, save in exceptional circumstances (for example, where the health or safety of others would otherwise be at serious risk)."

The duty of confidentiality owed to a minor is as great as the duty owed to any other person.

Research has shown that young people are often reluctant to approach their own GP with health problems, for fear that their parents will be told. A consequence is often that young people prefer to seek advice about sensitive matters such as contraception or drugs from specialist clinics, and do no allow those clinics to share relevant information with the general practice. This is detrimental both to the relationship between GP and patient and possibly also to the patient's health. To aim to improve young people's uptake of GP services, the Department of Health funded a working party of Brook Advisory Centres, the Royal College of General Practitioners, the Royal College of Nursing and the BMA to produce a confidentiality toolkit for general practice. The toolkit contains materials to promote the message of confidentiality within the surgery, training materials for health professionals and other practice staff and suggestions for informing young people of their rights.[2]

Limits on confidentiality

No patient has an absolute right of confidentiality, since the duty owed by health professionals must be balanced against the interests of the wider community. Thus there are a number of exceptional circumstances[3] in which any patient's confidentiality may have to be breached, for reasons such as the interests of public health or in order to prevent foreseeable harm to other people.

In addition, the GMC makes several comments which may be particularly relevant to children and young people:

"Problems may arise if you consider that a patient is incapable of giving consent to treatment because of immaturity, illness, or mental incapacity, and you have tried unsuccessfully to persuade the patient to allow an appropriate person to be involved in the consultation. If you are convinced that it is essential in the patient's medical interests, you may disclose relevant information to an appropriate person or authority. You must tell the patient before disclosing any information. You should remember that the judgement of whether patients are capable of giving or withholding consent to treatment or disclosure must be based on an assessment of their ability to appreciate what the treatment or advice being sought may involve, and not solely on their age."

The duty of confidentiality extends beyond a patient's death, and doctors should not reveal information about a patient which the patient did not want disclosed. It is important, however, that parents are able to find out about the reasons for the death of a child. The GMC advises that "if a patient under 16 has died you must explain, to the best of your knowledge, the reasons for, and the circumstances of, the death to those with parental responsibility."[4]

Involving parents

Notwithstanding the duty of confidentiality, most patients wish to involve people close to them in treatment decisions. When the child is young, the parents, or parents and child together, make the decision. Depending on the circumstances of the consultation and the type of treatment, most young people also involve their families. In all cases involving competent young people, doctors should try to persuade young patients to allow their parents to be informed of the consultation but should not override the patient's refusal to do so. In the BMA's view, even when the doctor considers the young person is too immature to consent to the treatment requested, confidentiality should still generally be maintained concerning the consultation. The BMA considers that doctors' duty of confidentiality is not dependent upon the capacity of the patient and, unless there are very convincing reasons to the contrary, the doctor should keep secret a minor's request for treatment such as contraception, even if the doctor believes the minor to be insufficiently mature for the request to be complied with.

In exceptional circumstances, the doctor may believe that the young person seeking medical advice on sexual matters is being exploited or abused. It is important for the doctor to provide counselling with a view to preparing the patient to agree, when ready, to confidentiality being relaxed. This task assumes greater urgency if the patient, siblings or other minors continue to be in a situation of risk so that in some cases, the doctor will have to tell the patient that confidentiality cannot be preserved. Disclosure should not be made without first discussing it with the patient whose co-operation is sought. To breach confidentiality without informing the patient and in contradiction of patient refusal may irreparably damage the trust between doctor and patient.

2 Health records

Definition of health record

Health records are those records made by health professionals in relation to the care of an individual patient. They include the notes made during consultations, correspondence between health professionals such as referral and discharge letters, results of tests and the interpretation of these, x-rays and other materials produced in the course of care.

Patient-identifiable photographs, taken for diagnostic purposes, also form part of the health record and must be subject to strict arrangements as to their confidentiality. Doctors should bear in mind also that competent minors can exercise a statutory right of access to their own medical records although material which the doctor considers damaging to the patient or material which identifies a third party other than a health professional involved in the patient's care may be withheld.

Access to and control of medical records

Babies and young children

In cases where a child cannot understand the nature of the application but parental access would be in his or her interests, the law allows such access. Parental access to a minor's medical record should not be allowed where it conflicts with the minor's interest. The Children Act 1989 emphasises the principle of consulting children and young people about any matter which concerns them closely. Any information which the child previously gave in the expectation that it would not be revealed, cannot be disclosed to any other person, although it must be noted that a doctor can exceptionally breach the confidentially of any patient if the doctor considers that there are sufficiently serious grounds to justify it.

There may be a conflict between the duty of confidentiality the doctor owes to the child and the parents' claim to exercise parental rights. This is of particular relevance in cases of suspected child abuse. Doctors must put the child's interests first but do all they can to avoid compromising the interests of other parties. Current emphasis is on working with parents, whenever possible. Once a guardian ad litem has been appointed by the court, his or her views and consent can be sought.

Parents' responsibility for children does not cease when married parents separate. In such cases either parent can apply for access to information about the child, subject to the previously stated limitations, unless specific prohibitions have been imposed by the courts. Parental responsibility is defined in chapter 2.

GPs in particular can find themselves in a difficult position where parents independently of each other want information about their young children's health care. A common enquiry to the BMA is families in which the parents are separated, and the parent the child is not living with wants to be contacted each time their child comes to the surgery. The terms of service of GPs do not require them to comply with such requests, which could entail a lot of time and resources if children present frequently. In such cases, the BMA advises doctors to try to persuade parents to agree to communicate with each other over their child's health. Doctors may also be willing to agree to contact the absent parent if something serious arises. In any case, both parents may apply for access to the health record at any time and doctors are usually prepared to discuss the child's health informally without requiring that the procedures required by the legislation are followed. The aim is the ensure that both parents are involved in the child's health care without imposing a disproportionate burden on the doctor. Only if disclosure to either parent would be contrary to the child's interests should information be withheld.

Competent young people

In law, patients who are capable of understanding what is entailed have a right of access to their own health records. The age of the patient is not relevant to his or her right of access. If patients are minors and capable of giving consent, parents[5] can apply to have access to their records only with the minor's consent. Ideally, parents should help young people to make medical decisions and should be aware of information in the minor's record. In some cases, however, minors may wish to keep secret from their parents some of the matters they have raised with their doctor. It is possible that parents may place pressure on children to authorise access to their records. Contraceptive advice, examination for sexually transmitted diseases, assistance in stopping smoking or drug abuse are examples of matters which minors may wish to conceal from parents. Sometimes children seek advice from the doctor on such matters, not because their behaviour puts them at some health risk, but rather because they are worried about other family matters or have a mistaken view of what is actually involved. Consultations on such issues may be recorded in the patient's file and doctors may believe that the minor is under pressure to grant disclosure. When parental access is authorised by the minor in such circumstances, the doctor may wish to talk to the patient separately from the parents to ensure that consent is voluntary. In all cases, doctors should encourage minors to share information with their parents.

Children and young people can authorise access to their records if they understand the concept of access. A problem which arises often is that of the minor who has been prescribed contraception and who then refuses to allow her doctor to grant parental access to her medical record, even though the doctor believes this to be in her best interests. Since the decision to prescribe in such cases turns on the capacity and understanding of the patient, it would follow that a patient capable of making up her mind about contraception should also be able to control access to her health record. More difficult perhaps is the case of a minor whose record shows she requested contraception which the doctor declined to prescribe on grounds of her lack of comprehension of what was involved. Such decisions are subject to the doctor's clinical judgement in each individual case. As a general principle, the BMA considers that doctors' duty of confidentiality is not dependent upon the capacity of the patient. Unless there are very convincing reasons to the contrary, the doctor should keep secret a minor's request for treatment such as contraception even if the doctor believes the minor to be insufficiently mature for the request to be complied with.

3 Circumstances in which confidentiality may need to breached

Confidentiality and suspected abuse

A child or young person who comes to a doctor with a suspicious injury should be the focus of the doctor's concern - not the family. Some doctors say that they feel a divided loyalty when they have as patients other members of the family, including the alleged abuser. Adults responsible for providing care, including doctors, retain a duty to intervene if a child or young person appears to be exploited or abused. When such cases arise, the child or young person who seeks help must be the priority, although the doctor must also bear in mind the safety of siblings who might also be at risk. Doctors must also be alert to the possibility of abuse of children in institutions.

Children often try and elicit a promise of confidentiality from adults to whom they disclose information about abuse when, in fact, they really want something to be done, rather than their plight to be kept secret. This is a common situation, which teachers, in particular, encounter, since they are often the first recipients of such information. Like teachers, doctors should not promise to keep the information confidential if the child's safety is in any way threatened. Doctors may find it helpful to call upon the skills and expertise of other members of the health team but neither doctors[6] nor other health-workers have any statutory powers to intervene and so are unable to protect a child or young person from continuing abuse. If there are safety protection issues to be considered, the matter has to be passed to an agency with statutory powers - social services or the police but, wherever possible, this option should first be discussed with the patient.

In most cases, children disclose to adults the facts of their abuse because they want the abuse to stop but doctors alone do not have the power to do this. Doctors should familiarise themselves with relevant guidelines[7] and be aware, for example, of the work of Area Child Protection Committees. The overall welfare of the child or young person must be the paramount consideration but, as stated earlier, the minor's own views are not necessarily the final arbiter in making ethical decisions.

Child protection case conferences

The question of sharing information at child protection case conferences also raises dilemmas for doctors. The role of the doctor in such fora is seen as pivotal but frequently doctors are intensely sceptical of the possibility of limiting the dissemination of information. Only information which is relevant to the purpose of the case conference and in the best interests of the child should be disclosed. Doctors will occasionally have to request that certain information is given in a limited forum or in writing to the chairman of the conference. Such measures should be used selectively for highly sensitive information and be avoided as regular practice.

The child's interests must be regarded as paramount and, if possible, the child's consent to disclosure obtained. The consent of parents or carers to disclosure should also be sought as appropriate and their consent is particularly important if disclosure relates directly to them such as information about their physical or mental health. (See also Chapter 7).

4 Use of health information for purposes other than health care

Research and teaching

The general issues concerning use of identifiable and anonymised data in medical research are discussed in Chapter 7.

Legal purposes

Doctors may need to seek a minor's consent for procedures other than treatment, such as the taking of photographic records, particularly in relation to documenting child abuse. In the case of young people and children capable of understanding, doctors should explain the reasons why photographs need to be taken. Often they may be taken for clinical reasons and repeated photographs in different lighting conditions may be required. In this situation the doctor has control of the procedure, which should be at a pace acceptable to the subject. If they are taken for evidential reasons, the police will take them and the doctor will have no control over the process.

If a child or young person refuses examination or photography, the doctor must make a careful judgement of how critical is the need for such procedures. Usually, they should not be performed contrary to the patient's wishes as this may cause further trauma. In a minority of cases, there may be an urgent imperative such as the assessment of the future safety of the child or siblings and it is then permissible for examination to proceed contrary to the patient's wish. It is emphasised that this should be exceptional and the doctor would need to be convinced that proceeding was in the patient's best interests. Gaining consent in such contexts may be a slow process and will require the doctor to talk the situation through with the patient and provide reassurance.

Video-taped material

Similar rules concerning consent and confidentiality must apply to video-taped material. These may be summarised in the following points:

- Where two-way screens are used either to monitor or film interviews, all individuals so monitored should be informed in advance and should know precisely who is observing them.

- Doctors must be sure of the purposes for which videos or photos are taken and decide whether such purposes are valid.

- Identifiable material should be treated with the same confidentiality as other medical records.

- Valid patient consent should be sought. If a child/young person is recorded on film, video or photograph, that person's consent for retention or use of the material must be re-confirmed at a later date when the patient is mature.

- Consent should be specifically sought for each and every purpose to which the illustrative record is put; this includes specific consent for use in teaching.

- Ideally such records should be made by registered medical illustrators, subject to a strict code of practice. Such people are usually aware of the potential difficulties involved and can help minimise the unease of the child or young person.

If a third party is featured (other than a health professional) the same rules of consent and confidentiality as for that person's other records apply.

- Videoed interviews should not be over-long and must be carefully managed. In efforts to capture film of inter-action, interviews have sometimes been unnecessarily protracted.

- When a medical interpretation of filmed behaviour or clinical examination is to be discussed, such interpretation must be left to doctors.

To benefit other people

Genetic information

The use and disclosure of genetic information is discussed in chapter 7.

Media and publicity

Images of sick children may be used in the media for a whole range of purposes, most of which do not aim to benefit the individual child but rather are to promote information about a particular condition or unit, or are purely for entertainment. Wherever possible, the BMA believes that information should be presented in a way so as to conceal the identity of the individual patient. Parents and children should both be involved in decisions about media contact. From an ethical perspective, the BMA has no objections to identifiable information about young people being used provided that the child's parents have given informed consent, the child agrees and it is not contrary to the child's interests either now or in the future.

Summary

Children and young people are entitled to medical confidentiality on the same grounds as other patients. This means that their rights are not absolute but can only generally be overridden when there is a clear justification, such as the risk of significant harm to other people. Where there is an exceptional reason justifying disclosure without consent, children should be told that their secrets cannot be kept. In the absence of any such reason justifying disclosure, they should be encouraged but not forced to share their health information with parents.

1. GMC, Confidentiality, October 1995.

2. {Add reference to toolkit}

3. Detailed guidance of the exceptional circumstances is provided in the BMA's document on confidentiality which is available on the website or in a paper version on request.

4. GMC. *Good medical practice*. London: GMC, 1998.

5. The term "parents" should be understood as including those, such as a guardian, who are legally recognised as exercising a parental role.

6. The discussion in this section applies to the situation in England and Wales only.

7. A number of specific guidelines have been published, including *Working Together Under the Children Act 1989*, HMSO, 1991, and *Child Sexual Abuse, a Guide to the Law*, published by the Children's Legal Centre, 1992.

Chapter 4: Involving children and assessing a child's competence

We have emphasised that all children and young people who are capable of expressing preferences should be involved in decision making, whether or not they are willing or able to take decisions which the law recognises. This raises questions, however, about the difficult task of trying to ascertain when a particular person is ready to accept information and make decisions affecting his or her life. As chapters 1 and 2 have discussed, seeking consent from children is not only about getting doctors the legal protection valid consent to treatment provides. It also ensures that children are involved in decision-making. In this chapter, we look at ways to involve children and enhance their ability to contribute to decision making, and also at the formal assessment of a child's competence to take a particular decision.

Defining competence is discussed in section 3.2 (below), but in general terms, a child under 16 has the legal capacity to give consent if he or she has sufficient understanding and intelligence to understand fully what is proposed. People over 16 are understood to be competent if they are able to understand in broad terms the nature and effects of the proposed treatment. The greater degree of understanding the courts demand for refusal of treatment is discussed further below.

Health professionals who assess ability to take valid decisions need to be skilled and experienced in interviewing children and eliciting their views without distortion. The treating doctor may be the most appropriate person, but other members of the health care team who have a close rapport with the child have a valuable contribution to make. Any person whose opinion contributes to a formal assessment should understand the nature of the legal tests required. Where the courts are involved in competence and best interests decisions, it is usual to seek an additional opinion from a doctor acting as expert witness rather than rely solely on the treating team's assessment of competence.

The guidance given below does not distinguish between hospital and general practice, nor between elective and emergency treatment. This means that not all of the factors listed will be relevant or appropriate in every circumstance. Similarly this chapter does not repeat the discussions of differences between consent and refusal which are found elsewhere in this book (see chapters 1, 2 and 5). It is important to note, however, that capacity is task specific, and health professionals must look at the consequences and gravity of a decision when considering whether a child has the competence to make it.

4.1 A practical approach to assessing competence

- Competence is dependent on the task in hand. It is constantly reassessed as a child faces fresh treatments, tasks or challenges.
- Children of the same age will differ significantly in their ability and willingness to participate. It is important not to approach the child with preconceptions about ability.
- Ability to participate can be enhanced by allowing time for discussion and ensuring that information is provided in a way which is appropriate for the child.

- Consent, like treatment, is a process and not a single event, and doctors often have an ongoing relationship with a child patient which allows for sound judgments about competence over time.
- Unless there are time constraints because of the nature of the child's illness, adequate time should be set aside to able to explore the question of competence.
- In some cases, a second opinion from a senior and experienced clinician may be helpful.
- Doctors should be clear what test of competence is being applied and the nature of the task the child is being asked to accomplish.
- Background information about the child which is relevant to the test should be obtained in advance, if possible. In particular, details about the child's daily life and experience of illness may be helpful.
- Information from parents or carers who know and love the child is of great importance, although doctors should be wary of relying solely on what could be an overly subjective view. Other people, for example teachers, play-specialists, nursing staff and social workers, may be in a good position to provide an objective appraisal.
- Where GPs have known the child for a long time, they may be well placed to evaluate competence and provide important information to other professionals about this.

Assessment
Assessment of competence to take a specific decision regarding health care or treatment needs to be based on how that decision is dealt with rather than on any standardized tests (although these may be useful in alerting professionals to the possibility that a child is unusually mentally advanced or delayed in comparison with others of the same age).

- Cognitive development: A number of structured tests may be used but whilst they provide general information they may not be task specific.
  a) The child should demonstrate a clear concept of him/herself in relation to other people as shown by an ability to recognise his/her own needs and the needs of others. This can be achieved by talking about relationships with parents, siblings, relatives and peers.
  b) The child should recognise and understand that there is a choice to be made and show a willingness to make it. That choice might be to ask another person to take decisions.
- Ability to balance risks and benefits of treatment: Some abilities develop as much by experience as by cognitive development. The assessment should look to whether the child has:
  a) an understanding of what the illness means and that treatment is needed;
  b) an appreciation of what the proposed treatment involves and what the intended outcomes will be; and
  c) an understanding of the implications of both treatment and non-treatment and the consequences.

The degree of understanding or more particularly the information necessary to balance risks of present or future harms and benefits may vary with the complexities of the treatment proposed. Experience shows that even young patients of, for example, five years of age, may have a relatively sophisticated understanding of the consequences of very complex interventions, although others argue that they may lack insight into the long term consequences. Children might demonstrate their understanding by talking about their illness, by asking questions which show that they understand, or in response to direct questions from others. Play or drawings might also be a way for children to reveal their level of understanding.

- A child who has competence to take health care decisions should have some concept of him/herself over time, which might be demonstrated by talking about hopes and fears for the future.
- Unwillingness to participate should not be interpreted as incompetence. A child who is competent to make his or her own decisions may nevertheless choose to allow parents to make decisions on his or her behalf. This demonstrates the ability to choose.
- Whether or not information is retained for long enough to make an informed decision is important. This can be tested by asking questions about the information which has been given. A child may become irritated or bored by this in the same way that adults do but this is not evidence of incompetence.
- Some children are clearly incompetent by reason of immaturity or lack of the ability to communicate their wishes. Extreme care is necessary, however, in making the assumption that an inability or unwillingness of a child to communicate with a doctor indicates incompetence.
- Doctors must be aware that their role as assessor can radically change the doctor-patient relationship and if not handled sensitively could undermine trust, confidence and mutual respect on which such a relationship should be founded.

Parents

- Children should be encouraged and given opportunities to discuss their health for themselves. This is particularly important for older children who may wish to discuss treatment without their parents.
- If cultural factors appear to be restricting the opportunity for exchange between doctor and child, for example if parents are unwilling to involve their child in decisions, doctors may have to explain why the child's involvement is important. Where families are not used to working in this way, changing views and culture may require a great deal of time and sensitivity.
- Conflicts between parents, carers and children may occur over what treatment should be given, and can hinder a child's ability to make a free choice. Discussion and attempts at achieving consensus can help.

4.2 Defining competence

As chapter 2 has shown, competence rather than age determines whether minors can give consent to medical treatment which is valid in law. All people over 16 are presumed to be competent to give consent[1] and those under this age may demonstrate their competence by meeting standards set by the courts.[2]

Adult patients are competent to consent to medical treatment if they are capable of understanding, in broad terms, the nature and effects of the proposed treatment.[3] They can do so for reasons that are 'rational, irrational or for no reason'.[4] When it comes to refusal of treatment, the courts look for a greater degree of understanding. In a case involving refusal of medical treatment by a schizophrenic patient, it was held by the High Court that a patient could refuse treatment if he or she could:

- comprehending and retaining treatment information;
- believing it; and
- weighing it in the balance to arrive at a choice.[5]

This definition of adult competence was further developed in the case of *Re MB* where a patient's refusal to undergo a necessary Caesarian section was overridden on the grounds of lack of capacity.[6] The Court of Appeal in that case stated that a person lacks capacity if some impairment or disturbance of mental functioning renders him or her unable to make a decision whether to consent to or refuse treatment. The court went on to state that that inability arises if the patient is unable to comprehend and retain the information which is material to the decision, especially as to the likely consequences of having or not having the treatment in question; or the patient is unable to use the information and weigh it in the balance as part of the process of arriving at the decision.[7]

The test set out in the case of *Re MB* departs from the test established in the High Court (above) by requiring that the incapacity must be as a result of 'impairment or disturbance of mental functioning'. It is arguably less helpful, therefore, than the previous tests in regard to young people, where a lack of capacity may be due to other factors, such as insufficient development or a lack of experience and information on which to base a decision. The test in *Re MB* also departed to the extent that it included no specific requirement for the patient to believe the information.

When it comes to children, the courts have looked separately at those under 16 and those 16 years and above. Young people between 16 and 18 years of age are competent to give valid consent to treatment if they meet the same test as adults (if they understand in broad terms the nature and effects of the proposed treatment). They do not, however in a position to have a right of veto over treatment since consent may be obtained from another source (see chapter 2).

Children under 16 must meet the standard of competence set in the *Gillick* case. There, the House of Lords said that a child can make legally valid health care decisions if he or she has sufficient understanding and intelligence to enable him or her to understand what is being proposed.[8] The High Court has also been clear that the test is whether the patient under 16 is capable of making a choice, not whether it was a wise choice.[9]

4.2.1 Coercion and undue influence

In addition to being able to make the relevant decision, a competent decision must be free from undue external influences. Factors which might cause a person to lack capacity include fear, confusion, shock, pain, fatigue, drugs, illness, medication, false assumptions and misinformation.[10,11]

Influence is a particularly important consideration in assessing children's competence. Parents are very influential on a child's view of treatment. It has been shown that parental attitudes to aversive treatment affect the likelihood of the child agreeing.[12] That is not to say, however, that children's decisions made with advice from their parents are necessarily invalid. In the vast majority of cases people make decisions in consultation with people close to them and yet final decision remains their own. What is important is whether the decision is the patient's own independent choice.

4.2.2 The functional nature of capacity

The definitions and the court's analysis of decision-making capacity show that the ability to take valid decisions is dependent upon the decision in question. It depends on the nature and complexity of the decision or task, and the person's ability to understand, at the time the decision is made, the nature of the decision required and its implications. Thus the graver the impact of the decision, the commensurately greater the capacity needed to make it. As chapter 2 has shown, the courts demand a very high level of capacity to take the decision to refuse consent to life-prolonging treatment although even a competent refusal by a person under 18 may not be determinative.

4.3 Growth in children's level of understanding

It is generally accepted that as children grow older, their mental abilities, social understanding and emotional appreciation increase.[13] The degree to which this is due to development, experience and social context is a rich source of research and debate. It is clear, however, that the increase in mental abilities reflects several different features, including knowledge base, ability to use more of the information available, more sophisticated mental planning capacities in order to decide how best to tackle decision-making, and increased flexibility in the use of mental strategies.[14]

As childhood progresses, children develop the capacity to make inferences about the causes of events.[15] The ability to understand what other people are thinking also increases,[16,17] as do planning and strategic thinking.[18] Research has shown that children as young as 5 use understanding which adults rely on throughout life.[19]

At all ages, there are marked individual differences between children. Comparisons of the widely differing childhoods which children experience in different parts of the world challenge 'universal' concepts that children develop along a single pattern of milestones.[20] Anthropological research with children in many different societies illustrates how children's behaviours differ depending on the expectations and endorsement of their society.[21] For example, the often described temper tantrums of two year old children are unknown in some societies. Children who are regarded as disadvantaged, such as those with chronic illness or disability, refugees, stigmatised or street children may have opportunities to show their courage and maturity in ways which sheltered children do not.[22] Yet the disadvantaged but competent children are not necessarily exceptional. Rather they live in exceptionally challenging circumstances which reveal capacities that are latent in most children.

Despite individual and even societal differences, it is possible to make some broad generalisations about stages of child development. On the whole, younger children are more prone to be misled by leading questions and a wish to please adults.[23] By early adolescence, young people's thinking tends to have become more abstract, multi-dimensional, self-reflective and self-aware, with a better understanding of relative concepts. This brings the ability to hold in mind several different dimensions of a topic at the same time, and so generate more alternatives in decision-making. In addition, children as they develop become better able to monitor their own thinking for inconsistency, for its gaps in information, and for the accuracy of its logic. This greater mental sophistication that comes during the teenage years is accompanied by related developments in the ways in which young people think about themselves. During adolescence, there is a marked increase in emotional introspection, together with a growing tendency to look back with regret and to look ahead with apprehension. That is, not only do young people become increasingly able to consider the long term consequences of their own actions, and of what happens to them, but also they tend to think about such consequences more in terms of their own sense of responsibility and better awareness of the effects of what they do on other people.

4.4 Factors affecting competence

Decision-making is influenced by both cognitive capacity and emotional understanding and these two aspects of functioning do not necessarily develop with the same timing. Emotional factors and experience are extremely important, and there is huge individual variation both in the time taken to reach particular mental levels and in the ultimate levels attained. Accordingly, no rule about competence that is based on just chronological age can possibly be satisfactory. This is true even for adult patients, where although people over the age of 18 are presumed to be competent, the presumption is rebuttable and decisions from people who lack capacity are not determinative.

Standardized tests of children's understanding may under-estimate what children can and do achieve in more ordinary day to day situations.[24] This variation in mental performance is even more marked when people's everyday experiences are unusual.[25] People tend to be very much better at solving problems when they concern issues familiar to them than when exactly the same problem is presented in an unfamiliar fashion. Also failure to solve a mental problem does not necessarily mean that the relevant cognitive skill is missing. If children can be helped with remembering different facets of a decision-making task, or if they can be shown how to adopt a different mental strategy, they may solve problems that are not ordinarily possible for children until a much older age.[26]

Much the same applies in the field of emotional understanding. Quite young children express mixed feelings and as they grow older they increasingly gain insight into their own emotional lives and realize when there is emotional ambivalence. Also children learn a range of thinking techniques to control their emotions. But, this capacity is influenced by circumstances. For example researchers have found children experiencing distress in hospital were less able than other children of the same age to appreciate mixed feelings.[27]

Even with the most detailed and skilled of assessments, capacity needs to be considered as a graded dimension and not as something that is either present or absent. Very young children of pre-school age are likely to have some appreciation of what is involved in their health care, although they may have only limited capacity to appreciate long-term consequences and to balance competing considerations.

4.4.1 The role of information

Giving and withholding information have been the subject of comment by the courts. In general, the courts have not criticised the deliberate withholding of information where it is believed that to provide it would cause extreme distress, as is shown by the case of A, previously mentioned in chapter 1.

A was nearly 16 years old, and suffering from leukaemia.[28] He urgently needed a blood transfusion as a life-saving measure. He and his parents, however, had refused consent to this being devout Jehovah's Witnesses. Although the boy knew that he would die if he did not receive the transfusion, nobody had told him how prolonged and painful his death would be. The judge in the Family Division of the High Court therefore concluded that whilst he clearly had sufficient intelligence to be capable of making decisions about his own well being, 'there was still a range of decisions the full implications of which A was still insufficiently mature to grasp'. Thus, it was concluded, he lacked the capacity to refuse.

The judge described how he put himself in the position of the 'ordinary father and mother' to reach a decision, based on A's welfare which included A's own wishes (as required by the Children Act) together with the particular circumstances and the religious community within which he lived. In this context, it was ruled that leave should be given to the hospital to carry out such treatment as was deemed appropriate, including blood transfusions.

Following the case, A continued to express his rejection of treatment, and when he reached adulthood, he exercised his right to refuse further transfusions and died.

Re E (A minor) (Wardship: Medical treatment)

In the case of *Re L*,[29] a 14 year old girl who suffered with epilepsy refused a blood transfusion after she had been severely burnt by falling into a bath of scalding hot water. If she was not operated on, the medical evidence showed that she would suffer gangrene and a slow and horrible death. L and her parents were Jehovah's Witnesses, and it was on religious grounds that L refused to accept the treatment. It appeared that the parents had not been asked to give their consent, presumably because their refusal would place more pressure on their daughter to adhere to the requirement of their faith.[30]

It was clear that L had not been appraised of the true consequences of refusing the proposed treatment. She was found by the high court to lack competence with respect to this decision, and the court authorised the transfusion to go ahead.

Re L (Medical treatment: Gillick competency)

The courts almost always consider life-saving treatment to be in the child's best interests. Given the tenor of previous judgments (see chapter 2), it is perhaps not surprising that there are no reported cases in the UK in which the courts have upheld a young person's refusal of a blood transfusion. Similarly, no refusal of a life-prolonging blood transfusion on behalf of a child by a parent has been upheld.

It is arguable that the young people in these cases were offered no real opportunity to consent. Information pertinent to the decision in question was, albeit for compassionate reasons, withheld from them so they stood no realistic chance of being assessed competent to make the decision. These cases have been interpreted by some as professionals imposing incompetence on children by withholding the information necessary to make competent choice.[31] The assessment of whether a child is competent thus also requires an assessment of the quality of the information and support offered by carers. These cases can be seen, however, as the courts not insisting upon a full evaluation of the child's competence where it might be contrary to the child's best interests to do so. Where the harm of disclosure outweighs the value of seeking a competent decision, doctors may be justified in withholding relevant information. It is arguable that such a justification may be difficult to reconcile with the unlimited right to participate reflected in Article 12 of the UN Convention on the Rights of the Child.[32]

Essential information

As with patients of any age, how much information should be given to children depends on the individual child. In general terms, the BMA believes that the following clear and simple explanations are relevant:

- An explanation or account of their condition/illness and how it will affect them, for example large inflamed tonsils as a cause of sore throats and pain on swallowing.
- A statement of the investigation or treatment which is proposed and what effect it may have on them. This should include an explanation of the risks and benefits, and chances of each occurring.
- A simple account of the risks and benefits of alternative, deferred or no treatment.
- The practical consequences of treatment to themselves in terms of social inconvenience, altered life style, schoolwork and so on. These should include details which children find important, for example the palatability of drugs, use of needles and blood tests, effects on mobility, absences from school, effects on friends and how pain will be relieved.

In some circumstances, parents, carers and health professionals may agree that it is not in the child's best interests to be told precise details of their diagnosis, although this is the exception, not the rule. A decision to withhold some information should not prevent the treating team from explaining in general terms the need for treatment and procedures and obtaining the child's agreement for these. Children need to feel that the treatment, however unpleasant, is better than the untreated illness.

4.5 Enhancing competence

Doctors are aware both that competence can fluctuate and that there are many factors which influence the ability to make competent decisions. Barriers to competence and involvement can be overcome by providing the best opportunity for children to participate. The following suggestions and points may be helpful.

- Children may find decision making easier if it is broken down into sub-tasks. It is possible that a child will be able to carry out some of these tasks competently, but not others.
- Communication difficulties may result from physical disabilities, but can often be overcome. Careful assessment of speech, language functioning, hearing and sight can identify any potential barriers to communication. Translators should be used where necessary, and should usually not be a member of the family, although in some cases this may be unavoidable. Independent translators can have an advocacy function, if appropriately trained.
- Written and other forms of recorded information can be helpful, and younger children may benefit from the use of play, drawings, games and puppets to help understanding.
- Children and young people differ, and may change their minds about the benefits of having a third party present in consultations and discussions. The capacity of some children is enhanced by having a parent, carer or trusted member of staff present, but the same child should also be given opportunities to speak to the doctor or health care team alone.
- The venue should be non-threatening, welcoming and child focused but not distracting. Anxiety about unfamiliar surroundings may mean that a child becomes frightened and less able to participate. When undertaking a formal assessment of competence, it may be preferable to talk to the child in his/her own home. A relative or carer may be able to identify the most suitable venue.
- The doctor-patient relationship should be sympathetic, supportive and objective. If the relationship is authoritarian the child may be inhibited from expressing views and may therefore appear to lack competence.
- The way in which the child is approached and dealt with generally can have a significant impact upon willingness to participate and capacity to do so. Health professionals are usually sensitive to this.
- Awareness of the family's usual pattern of decision making can be helpful; is it usual for children to play a significant part in decision making, and if not, how can they be

encouraged to take on this role in the current situation?
- Vulnerability to coercive influences should be acknowledged and minimised.
- Competence and simply the ability to participate can be enhanced with treatment or symptom management. For example management of pain or treatment of encephalopathy can mean children are more able to take part. Similarly the effects of medication, for example euphoria induced by systemic cortico-steroids, can affect competence. Whenever possible children should be given the opportunity to express their views when the effects of medication are absent or at a minimum.
- Decisions should be delayed wherever possible and discussed when a child is best able to participate. Where capacity fluctuates, children should be consulted when they are at their most lucid and able to participate.
- Depression and anxiety can be difficult to recognise, but may interfere with competence. Where there is doubt about a child's mental state, a psychiatric opinion is often helpful.
- Competence is likely to improve over time, both as the child learns and understands more about health and treatment, and, more generally, as the child matures. Assessments of competence undertaken in the past are therefore unlikely to reflect a child's current ability to participate.
- If a child refuses to participate in health care decisions, efforts should be made to understand why this is the case and to overcome any difficulties or misapprehensions.

4.6 Summary

This chapter has set out some basic principles regarding competence, its assessment and involving children.

- Children under 16 are competent to give consent to medical treatment if they have sufficient understanding and intelligence to understand what is being proposed.
- Between 16 and 18, young people are competent to give consent if they understand in broad terms the nature and effects of the proposed treatment.
- The refusal of even a competent person under 18 may be overridden by somebody with parental responsibility or a court.
- Competence is function specific. Doctors must therefore be aware of the task in hand when considering a young person's competence to make a decision.
- Whilst some children clearly lack competence due to immaturity, doctors should not judge the ability of a particular child on the sole basis of his or her age.
- Doctors should provide a child with as much information about the illness and prognosis as is appropriate for that child.
- Doctors should take steps to enhance the ability of children to participate, and encourage them to do so.

In practice, formal assessment of competence as a discrete process is rare. Judgments about whether a child is competent to make a particular decision might be necessary if he or she presents for treatment alone, is to make the decision whether to accept or reject treatment options, or gives consent where parents refuse. The issue is less important in a legal sense if decision making involves the whole family, and decisions are taken jointly.

The issues raised in this chapter, however, are about more than assessing competence. There are strong ethical and clinical obligations to encourage children to be involved in their health care to the extent that they are willing and able to do so. Using the techniques described here to enhance competence and facilitate participation are important aspects of good clinical care. Whilst these may appear to impose a considerable burden on the health care team in terms of being time and labour intensive, professionals should recognise that there is an increasing public demand for candour in health care. Educating, informing and involving children in health care decision making is an important investment with immense future potential benefits for the health service, its staff and its patients.

1. Family Law Reform Act 1969 s8(1). Age of Majority Act (NI) 1969.

2. *Gillick v West Norfolk and Wisbech Area Health Authority and another* [1985] 3 All ER 402.

3. *Sidaway v Board of Governors of the Bethlem Royal Hospital and Maudsley Hospital* [1985] AC 871 {get ref}.

4. *Sidaway v Board of Governors of the Bethlem Royal Hospital and Maudsley Hospital* [1985] AC 871 {get ref}.

5. *Re C* [1994] 1 All ER 819.

6. *Re MB* (Medical treatment) [1997] 2 FLR 426, [1997] Fam Law 542, FD.

7. *Re MB* (Medical treatment) [1997] 2 FLR 426, [1997] Fam Law 542, FD.

8. *Gillick v West Norfolk and Wisbech Area Health Authority and another* [1985] 3 All ER 402: 403.

9. *South Glamorgan County Council v B and W* [1993] 11 BMLR 162: ?.

10. *Re T (Adult: Refusal of treatment)* [1992] 4 All ER 649.

11. *Re MB* (Medical treatment) [1997] 2 FLR 426, [1997] Fam Law 542, FD.

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Chapter 5: Non-treatment and refusal of treatment

5.1 When medicine cannot achieve the desired effect

Views differ about the legitimate or appropriate uses of medical skills, but the primary goal of medicine is widely accepted as being to benefit patients by restoring or maintaining their health as far as possible. Weighing benefit against the harms and risks of treatment requires a holistic approach, balancing not only the likelihood of the treatment achieving clinical success, its invasiveness and side effects, but also the wishes and needs of the child and family. Although the assumption will usually be to offer treatment where there is a chance of clinical benefit, when the balance of the likely burdens of treatment outweighs the expected benefits, striving to prolong life with invasive medical procedures may be inappropriate. The aim of the health care team then shifts to providing palliative care to ensure that the child has the best quality of life possible. How to identify the point at which the goal shifts is clinical, ethical and legal, and decision making requires safeguards and review. This section identifies the relevant factors to take into account in such decisions.

5.1.1 Benefit

The BMA is aware that views differ as to what factors should be considered in deciding whether continued provision of life-prolonging treatment would be a benefit to a child who is unable to express his or her own wishes. Some people believe that there is an intrinsic value in being alive and therefore that prolonging life will always provide a benefit to the patient regardless of any other factors. In this absolute form, this is not a view the BMA shares. The vast majority of children with even very severe physical or mental disabilities are able to, or may in the future, experience and gain pleasure from some aspects of their lives. Where it is clear, however, that disability is so profound that a child has no or minimal awareness of his or her own existence, no ability to interact with others, and no hope of achieving or recovering awareness, or where they suffer severe untreatable pain or other distress, the question arises as to whether continuing to provide treatment aimed at prolonging that life artificially would provide a benefit to them.

5.1.2 Life prolonging medical treatment

Advances in medicine continually extend the range of treatment options available to prolong life when organ and system failure would otherwise result in death. Ventilatory support, for example, could keep alive patients who cannot breath spontaneously. For some children, this allows time for natural recovery, but for others, while with treatment they may remain stable for many years, that can be with no hope of experiencing more than very minimal levels of awareness of their surroundings. Where there is no way to overcome an underlying pathology or a coincident pathology, and there is extreme pain and distress or minimal awareness, there may be no benefit to the child in prolonging life artificially.

Artificial nutrition and hydration is also a form of life-prolonging medical treatment, although the BMA recognises that many people perceive there to be an important distinction between this and other treatments. Artificial in this context means specifically ways of providing nutrition and hydration which bypass the swallowing mechanism, for example nasogastric tubes, percutaneous endoscopic gastrostomy (PEG feeding) and total parenteral nutrition. In recognition of how distressing and difficult these decisions are, and in order to reassure patients, their families and society as a whole that artificial nutrition and hydration is withdrawn or withheld in only those rare cases where provision would not provide a net benefit to the patient, the BMA proposes that there should be additional safeguards for decision making.

Oral nutrition and hydration, where food or nutritional supplements are offered into the patient's mouth, is an aspect of basic care. This and other aspects of basic care must never be withdrawn.[1]

In 1999, the BMA published guidance on decisions to withhold or withdraw life-prolonging treatment, which included additional safeguards for decisions about artificial nutrition and hydration. The following sections summarise the advice in that book. For a fuller explanation of the moral and legal reasoning behind these views, and more detailed guidance, readers are referred to the book *Withholding and withdrawing life-prolonging medical treatment*.[2] The Royal College of Paediatrics and Child Health has also issued guidance on decisions to withdraw or withhold life-prolonging medical treatment.[3]

5.1.3 Clinical factors to be considered

Where treatment is unable to achieve its intended clinical goal, or imminent death is inevitable, active treatment may provide no therapeutic benefit and may be withheld or withdrawn. The Royal College of Paediatrics and Child Health has identified clinical situations in which it might be necessary to consider withdrawing or withholding treatment.[4] These include situations in which:

- brain-stem death has occurred;
- the child is reliant on others for all care and does not react or relate to the outside world;
- treatment can only delay death with no significant alleviation of severe suffering;
- although the child may survive, there is extensive physical or mental impairment which it is unreasonable to expect the child to bear; or
- the burdens of further aggressive treatment for progressive and irreversible illness are believed by the child and/or family to outweigh the clinical benefits.

All treatment decisions must be based on the best available clinical evidence, and the BMA acknowledges that this can take significant time and resources. Factual information should be collected about the child's condition, diagnosis and prognosis, including the stability of the condition over time and the underlying pathology. Doctors must look to local and national guidelines on diagnosis and management, and to experienced colleagues if necessary, when assessing prognosis and considering treatment options.

Efforts should always be made to stabilise the child's condition to allow for proper assessment and consideration of the likelihood and extent of any expected improvement. Where there is reasonable doubt about the potential for benefit, treatment should be begun and the child's condition reviewed when the treatment's impact and effectiveness can be assessed. Openness with parents and carers about the purpose of initiating treatment in such cases is important in case a subsequent decision to withdraw it is necessary.

The assumption in the labour ward will always be to begin treatment to establish its effectiveness and assess the baby's condition before an informed decision can be made about how to proceed. Any deviation from this general rule will only be made where the evidence is clear that initiating treatment would be futile. Where it is apparent during pregnancy that questions about treatment might arise after the birth, the issues should be discussed in advance so parents and the health team are as ready as possible to make decisions.

Having collected the necessary information, the type of factors which should be taken into account in the clinical assessment of benefit include:

- clinical judgment about the effectiveness of the proposed treatment;
- the likelihood of the patient experiencing severe unmanageable pain or distress;
- the level of awareness the patient has of his or her existence and surroundings, and the likelihood of developing this;
- the likelihood and extent of any degree of improvement in the patient's condition if treatment is provided; and
- whether the invasiveness of the treatment is justified in the circumstances.

'Responsibility for the decision to withdraw or withhold treatment lies with the clinician in overall charge of the child's care. Decisions are made after discussion with the health care team, the family and others to the child. `

Where the decision relates to withholding or withdrawing artificial nutrition and hydration from a child or young person who is not imminently dying, the BMA recommends that there should also be formal clinical review of the decision by a senior clinician. The clinician should not be a part of the treating team, and should have experience of caring for children with the same condition. All such decisions should be available for subsequent clinical review to ensure that appropriate procedures and guidelines were followed. The BMA also recommends that anonymised information should be available to the Secretary of State on request, and, where applicable, to the Commission for Health Improvement.

The BMA believes that the same justification is required for continuing to provide a treatment as to provide it in the first place; that it provides an overall health benefit for the child. Although emotionally it may be easier to withhold treatment than to withdraw that which has been started, there are no legal, or necessary morally relevant, differences, between the two actions. In other words, the emphasis in making treatment decisions should be the reasons for providing it rather than the justification for withholding or withdrawing it.

5.1.4 Ethical factors to be considered

Doctors, children and informed parents share decisions about withdrawing or withholding life-prolonging medical treatment. Where the assessment of clinical factors does not provide a clear answer about whether the likely medical benefits of treatment outweigh its burdens, children and their parents are usually best placed and equipped to weigh the medical advice and apply it to their particular circumstances (see chapter 1 for discussion of best interests). The courts have affirmed the moral right of parents to decide by presuming that they are generally correct in identifying where their child's interests lie.[5] The courts have also emphasised the importance of agreement between parents, in particular where the procedure is controversial (see chapter on sensitive procedures).

As has been discussed in chapter 2 patients and their relatives cannot legally or ethically insist upon treatment which the health care team considers to be inappropriate or when the burdens of the treatment clearly outweigh the benefits for the child. Whilst it is entirely understandable for parents to want to prolong their child's life for as long as possible, the BMA's view is that for desperate parents to expose fatally ill children to all manner of painful, unproven or essentially futile treatments breaches the child's right to be free from such intrusion. The doctor's first duty is to the child and in such cases the main task may involve helping the family face reality.

Children's roles in decisions increase as their maturity and ability to express views develops. They should always be encouraged and helped to understand the treatment and care they are receiving and to participate in decision making to the extent they are willing and able. In almost every case, consensus about treatment will be reached between the child, if he or she is able to participate, parents and the health care team. A lack of consensus in decision making can result from poor communication and inadequate provision of information to all those involved in the decision, and doctors should ensure that this is not the case. Additional clinical opinions, and discussion with others who have experience of similar decisions can also aid the decision making process. Where serious disagreement remains after discussion, informal conflict resolution and additional advice, doctors are advised to seek the approval of a court before withholding or withdrawing life-prolonging medical treatment.

5.1.5 Legal factors to be considered

Decisions to withhold or withdraw treatment on the basis that it does not provide a benefit to a child should be made by the clinician in overall charge of care, following discussion with all appropriate parties. Where this view is seriously challenged and agreement cannot be reached despite every attempt to do so, the matter should be taken to court. The courts have also indicated that, for the time being, all decisions to withdraw artificial nutrition and hydration from patients in persistent vegetative state (PVS) or in a state of very low awareness closely resembling PVS should come before the courts. The courts made clear that this is an interim measure until a body of experience in dealing with the condition has developed, and until other effective mechanisms for decision making are in place.

The BMA believes that a considerable body of evidence has now been established regarding adult patients in PVS, and so hopes that in future the courts will decide that these cases no longer inevitably require court review. In general, reliance on widely accepted professional guidance, and robust mechanisms for decision making and review is preferable to involving the courts. Where uncertainty or disagreement remains, however, it will be necessary to involve the courts in decision about patients in PVS. Diagnosis of PVS is more difficult to make in child patients. In practice, therefore, uncertainty and disagreement will be more common in cases involving children. Although the BMA believes the same ethical principles apply and would eventually want to see these decisions made by clinicians and families, until there is a better evidence base about the condition in minors, and the similarities and differences between it and the condition in adults can be established, court review will provide a welcome safeguard for many who have to face these difficult decisions. Other issues around PVS are discussed in chapter 7.

A body of medical opinion has developed that it is appropriate in some cases to withhold or withdraw artificial nutrition and hydration from these patients, although the matter has not been before the UK courts. Whilst this means that the courts have not specified that they should review all cases of withdrawing or withholding artificial nutrition and hydration from patients not in PVS, lack of a clear legal guide on this issue arguably leaves doctors open to uncertainty and challenge. Particular care must therefore be taken to ensure that decisions comply with local and national guidelines, and accepted clinical practice. Cases of children who are minimally conscious but in a stable state raise very particular difficulties in relation to balancing benefits and burdens. Legal advice should be sought about these cases.

5.1.6 Once a decision has been made

When agreement has been reached that withdrawing or withholding treatment is best for the patient, all those involved in the decision, the child, parents, other relatives and health care team, should be informed of the decision and its basis. Such an explanation can help those involved in caring for the child to satisfy themselves that decision is right. It can also help those close to the child to come to terms with the situation. Such discussion gives advance notice of any disagreement about the child's care, and provides an opportunity to decide to seek further clinical advice or involve the courts if necessary.

It is essential to emphasise that the decision does not represent abandonment or 'giving up' on the child. It is the value of the treatment that is being assessed, not the value of the child. Although the immediate goal may, rightly, have shifted from seeking the benefits which arise from prolonging life to seeking those which arise from being comfortable and free from pain, the overall objective of providing benefit does not change.

A decision to withdraw or withhold treatment is never immutable. The situation and decision must be reviewed both before and after implementation to look for and take account of any change in circumstances. The decision, its basis and subsequent change must be recorded in the medical record, and the BMA recommends that decisions to withdraw or withhold treatment are an appropriate subject for clinical audit.

Where a member of the health care team has a conscientious objection to the proposed course of action, that person should, wherever possible, be permitted to hand over his or her role in the care of the child to a colleague. Family members and health professionals involved in the decision can be left with feelings of guilt and anxiety in addition to bereavement, and it is important there is support available both before and after the decision to withdraw or withhold treatment has been made.

5.2 Where there is not agreement about whether treatment should be provided

5.2.1 Refusal by parents

Most medical decision making for immature children is rightly left to parents and the health care team, and the courts are wary of intervening. It is widely agreed that parents need time, respite facilities, possibly counselling and certainly support from health professionals but in most cases, they are best placed to judge the child's interests and decide about serious treatment. Decisions should be child-centred and family-centred, taking into account the holistic situation rather than merely the medical aspects. For example where an invasive or painful treatment only appears to offer a limited extension of life, the overall best interests of the child may indicate that palliative treatment in a familiar environment is preferable. Notwithstanding the importance of the parental role, however, where it appears that the parents are following a course of action which is contrary to the child's interests, it is likely to be necessary to seek a view from the courts. In past legal cases, the courts have recognised a duty to protect children and authorise treatment where there is a good chance of it succeeding.

Although in law consent is needed from just one party, disagreements between parents can be very difficult for all concerned. Doctors propose treatment in the belief that it stands a good chance of providing a clinical benefit to the patient. Consent from one parent permits the doctor to proceed, and in law the onus must then be on the dissenting parent to take steps to prevent the treatment from being implemented.

In practice, doctors will not wish to override the strongly held views of a parent, particularly where the benefits and burdens of the treatment are finely balanced and it is not clear how to provide an overall net benefit for the child. Discussion aimed at reaching consensus should be attempted. If the dispute is over a controversial, elective procedure, for example male infant circumcision for religious purposes, doctors should not proceed without the authority of a court (see chapter 7).

5.2.2 Refusal by competent young people

As previous chapters have discussed, the law does not recognise people under the age of 18 as having the same rights as informed adults to refuse procedures which are necessary to prolong life or prevent serious deterioration in health. Nevertheless, as in all other situations discussed in this book, children and young people should have opportunities to be as informed as they want to be about the treatment options and prognosis for their condition. Refusal by a patient of any age who is competent and informed should be taken very seriously and treated with respect although it may be that in some cases a competent minor's refusal of treatment will be overridden.

Health professionals should ensure that they approach and talk to children in a way which encourages them to participate freely in decision-making. Over-emphasis on the importance and detail of a minor intervention may cause undue anxiety and distress, and making light of more serious procedures may mean the health professional is distrusted. The purpose of seeking consent from children is not simply to establish a legal authority to proceed. It is to allow children to be actively involved in deciding what is done to them. There is little point in pressuring children into saying yes, although they should be strongly encouraged to agree to what the clinical team and parents consider to be in their best interests.

If the anticipated outcome of a proposed procedure is relatively insignificant for the child in question, it is unlikely to be justifiable to override his or her wishes. Doctors should consider the impact of complying with a competent young person's refusal on his or her long term chances of survival, recovery or improvement. For example, young people who have had repeated chemotherapy which has not provided a significant improvement, and for whom there is uncertainty about the chances of achieving therapeutic benefit, may decide that they do not wish to repeat it. When deciding what is in young people's best interests where the likelihood of clinical success is uncertain, their informed refusal may tip the balance in favour of withholding further treatments. Where non-treatment would be life threatening or postponement would lead to serious and permanent injury, moral arguments for providing it against a young person's wishes are stronger than if the procedure proposed is elective or the consequences of not providing it are less grave. Doctors must balance the harm caused by violating a young person's choice against the harm caused by failing to treat.

5.2.3 Advance refusals

In its published advice on advance decision-making the BMA recognises that competent young people do not have the same legal rights to refuse in advance life-prolonging procedures through an advance directive or living will. They may, however, wish to express their wishes in advance in the knowledge that these will be given proper consideration. The BMA's published advice states that:

> *Competent patients of any age should feel confident that their views count and are respected. Children and young people do not have the same legal rights as adults and should be informed that, although efforts will be made to meet their wishes, in cases of disagreement about measures conducive to their welfare their own views will not necessarily be determinative. Discussion with young people should be structured so as to help them identify their own wants and needs but they should also be encouraged to take decisions jointly with those with whom they have a close relationship, especially parents.*[6]

5.2.4 Refusal of blood products

Jehovah's Witnesses have a conscientiously held religious opposition to the use of blood products for themselves and their children but are generally very anxious to cooperate in every way with alternative options. Most Witnesses will not accept their own blood donated in advance but may allow their blood to be diverted outside the body to be recycled during an operation, provided it is not stored. In recent years, great medical progress has been made in the development of 'bloodless' procedures, including in 1996 a successful organ transplantation without blood. Watch Tower, an international organisation for Jehovah's Witnesses, has published a summary of alternative therapies and references to the medical research which supports these.[7]

Jehovah's Witnesses draw attention to what they consider to be an excess of caution on the part of health professionals which is manifested in a too swift and unconsidered resort to the use of blood when other alternatives may be available.[8] The BMA recommends that health professionals should make every effort to accommodate such beliefs rather than resorting to the most obvious medical option which is contrary to the patient's wish or looking to the courts as a first option. It supports the following recommendations when faced with a refusal of blood products by or on behalf of a child or young person:

- It is important that health professionals ensure that the situation is truly life-threatening and that there are no other feasible alternatives to the use of blood.
- The child and the parents must be given an opportunity to put forward their views and have these considered.
- The local Hospital Liaison Committee for Jehovah's Witnesses should be contacted with the consent of the family or the competent young person. The Committee may be able to advise on possible alternatives.
- If health professionals involved in the case consider blood products to be the only solution they can offer to save the life of the child, the patient or the patient's family may request that treatment be transferred to another facility where bloodless treatment is practised. Such wishes should be accommodated where possible.

As with all refusals of treatment, if the patient is competent, informed and sure of his or her commitment to the decision to refuse blood, there are strong moral arguments for not overriding this. The moral imperative to follow refusal by parents is necessarily weaker than when children themselves make informed decisions. There should be careful discussion with the young person and family to ensure that he or she fully understands the situation. It is advisable for health professionals to discuss the issues and implications with the young person separate from other family members to ensure that a valid decision has been reached without any pressure.

Ultimately, where there is no alternative to the provision of blood, the courts are likely to override refusals by parents or competent minors in favour of preserving life (see chapter 2, section 2.4), although in reported case law to date the young person in question had been judged to lack competence.

5.3 Providing treatment when the patient refuses

As was discussed in chapter 2, the BMA believes that the cases in which it is necessary to override a competent young person's wishes are exceptional, and doctors are reluctant to impose treatment on any child against his or her clear wishes. Proceeding with treatment is lawful if there is consent from somebody with parental responsibility (see chapter 2).

However, this does not mean that treatment *must* be given, and the harms associated with imposing treatment on a young person who refuses, whether competently or not, will play a part in the decision whether or not to proceed. How critical the treatment is, whether alternative less invasive treatments are available and whether it is possible to allow time for further discussion with the patient are all factors which weigh in the decision. As much time as is practicable should be taken for discussion, and treatment should be delayed if that is possible without jeopardising its likely success.

5.3.1 Legal issues in the use of detention and restraint

The courts have been clear that the use of force and detention to provide medical treatment can be lawful in some circumstances. The principle is implicit in judgments overriding young people's refusal of treatment (see chapter 2), and was the subject of more explicit comment in a case involving an anorexic girl.[9]

A 16 year old girl, C, suffering from anorexia nervosa was a defendant in a case in 1997. She was receiving treatment at a private specialist clinic, but had a history of absconding. The clinic did not qualify as a hospital with powers of detention under the Mental Health Act, and so sought an order permitting the detention of C for the purposes of the provision of treatment. C was considered, by virtue of the nature of her condition, to lack the capacity to make decisions about her treatment.

The court held that C could be treated against her wishes and detained at the clinic for this purpose. Since C refused and was likely to attempt to abscond, the use of force to keep her at the clinic was authorised. It was acknowledged that detention was a "draconian remedy" and safeguards were required to ensure that force and restraint were the minimum necessary to achieve the aim, and that the period of detention should similarly be kept to a minimum. These safeguards were aimed at protecting C's welfare.

Re C High Court of Justice, Family Division

Detaining children in a health care facility, other than under the Mental Health Act, raises legal issues because restricting the liberty of children is controlled by statute. The Children Act provides that certain categories of children may be prevented from leaving a building or part of a building if a court determines that the criteria in the legislation are satisfied.[10] The provisions cover those children who are looked after by a local authority (in care or being voluntarily accommodated) and certain others including children accommodated by health authorities and NHS trusts.[11] Before making a secure accommodation order, the court must be satisfied that the child has a history of absconding and is likely to do so from any other accommodation and is either (a) likely to suffer significant harm if he or she absconds; or (b) likely to injure him or herself if kept in any other accommodation.

In addition to the issue of detention, in the case of C, Wall J was clear that the court's inherent jurisdiction permits authorisation of the use of force where treatment has been authorised against a young person's wishes. It has been noted that "once it is accepted that a competent patient's refusal may be overridden, in principle there cannot be an absolute prohibition on the use of force to effect the treatment to be carried out in her best interests".[12] Similarly, however, "merely because treatment is in a competent patient's best interests does not mean the use of force is".[13] The particular circumstances of a case and how best to promote the child's welfare in a broad sense are the overarching considerations.

5.3.2 Good practice guidance in the use of detention and restraint

Detention and restraint is rarely necessary when caring for children. Even where the child refuses consent to treatment, talking to the child and explaining why treatment is necessary will usually help the child to come to accept and cooperate with the decision. This was seen in the case of a 15 year old girl, M, who refused to give consent for a heart transplant.[14] She told her doctors that although she did not want to die, death was preferable to having another person's heart in her body and taking drugs for the rest of her life. The judge overrode her refusal, and authorised the doctors to proceed. He took great care to explain his reasoning in the judgment so M could see why her refusal was overridden. After the ruling, the Official Solicitor was reported as saying 'while one cannot say she accepted the judge's decision, she was, I think, resigned to the fact. She didn't challenge it in any way. I came as an enormous relief to her parents'.[15] (See chapter 1 for further discussion of this case.)

Having spent as much time as is practicable a child continues to refuse treatment, if it becomes apparent that restraint is needed in order to proceed or for reasons of safety, a number of issues arise.

- Restraint should only be used where it is necessary in order to provide essential treatment or to prevent a child from significantly injuring him/herself or others.
- Restraint is an act of care and control, not punishment.
- Unless life-prolonging or other crucial treatment is immediately necessary, the approval of a court should be sought where treatment involves restraint or detention to override the views of a competent young person, even where parental consent has been given.
- All steps should be taken to anticipate the need for restraint and to prepare children, their families and staff.
- Wherever possible, the member of the health care team should have an established relationship with the child and should explain what is being done and why.
- Treatment plans should include safeguards to ensure that restraint is the minimum necessary to achieve the clinical aim, and that both the child and parents have been informed what will happen and why restraint is necessary.
- Restraint should usually only be used in the presence of other staff, who can act as assistants and witnesses.
- Any use of detention or restraint should be recorded in the medical records. These issues are an appropriate subject for clinical audit.

The Royal College of Nursing (RCN) issues practical guidance on restraining children or preventing them from leaving (containment) which recommends that children and, where appropriate, parents and staff should be given the opportunity to discuss the incident as soon afterwards as possible.[16] The BMA supports the RCN's recommendation that policies on the use of containment and restraint should be developed.[17]

In addition to being difficult to achieve in practice, imposing treatment on young people where they refuse could be damaging to the young person's current and future relationships with health care givers, and could undermine trust in the medical profession. It is important for young people to understand that restraint of any form in order to provide treatment is only used as a matter of last resort, and not until other options for treatment have been explored. The child and family must be offered continual support and information throughout the period of treatment.

Members of the health team benefit from being given an opportunity to express their views, and to participate in the decision making, although ultimate responsibility rests with the clinician in charge of care. All staff require support, and should not be asked to be involved in restraining a child without proper training.

5.4 Summary

Decisions about whether treatment should be offered to a child and his or her family are commonplace. Assessment of the benefits a treatment is offering and balancing potential benefits in the light of the wishes of children and their families is a part of routine practice. The decisions become particularly difficult where the benefits and burdens are finely balanced, for example where there is a very slim chance that a very invasive treatment will give some chance of improvement in a serious condition, or when agreement about how to proceed cannot be reached by the family and health care team.

Although refusal of treatment by competent young people, and by parents, will be very influential, in some cases these will not be determinative. The aim of decision-making here is to achieve consensus amongst all involved with decisions about care, and in the rare cases where this cannot be achieved despite all efforts, it may be necessary to ask the courts to intervene.

In particular, this chapter has highlighted the following points:

- There is no obligation on health professionals to provide medical treatment which cannot achieve its clinical aim, or which does not provide an overall benefit to the child.
- In deciding whether treatment should be begun or stopped, health professionals must act within the law and will take the lead on assessing the relevant clinical factors.
- Decisions about best interests more broadly will be made by families, with the influence of the views of young people growing with their maturity and understanding of the decision.
- Support for the child, family and health care team is essential throughout the process of deciding about the provision of life-prolonging treatment, and during and

following its implementation.

- Constant review of the child's condition is essential, and all decisions and changes to the child's circumstances should be documented in the medical record.
- All efforts should be made to overcome disagreements about treatment.
- Providing treatment to a competent young person against his or her wishes may require the approval of a court, particularly if providing it requires the use of restraint or containment.
- The harm caused by violating a competent child's choice must be balanced against the harm caused by failing to treat.

1. The BMA defines basic care as "those procedures essential to keep an individual comfortable". British Medical Association. *Advance statements about medical treatment*. London: BMJ, 1995: 6.

2. British Medical Association. *Withholding and withdrawing life-prolonging medical treatment*. London: BMJ, 1999. The full text of this publication can be found at www.bmjpg.com/withwith/ww.htm.

3. Royal College of Paediatrics and Child Health. Withholding or Withdrawing Life Saving Treatment in Children: A Framework for Practice. London; RCPCH, 1997.

4. Royal College of Paediatrics and Child Health. Withholding or Withdrawing Life Saving Treatment in Children: A Framework for Practice. London; RCPCH, 1997.

5. *Re T (A minor) (Wardship: medical treatment)*; sub nom *Re C (A minor) (Parents' consent to surgery)* [1997] 1 All ER 906.

6. British Medical Association. *Advance statements about medical treatment*. London: BMJ, 1995: 13.

7. Watch Tower Bible and Tract Society of Pennsylvania. *Family care and medical management for Jehovah's Witnesses*. New York: Watch Tower Bible and Tract Society of New York, 1995.

8. Watch Tower Bible and Tract Society of Pennsylvania. *Family care and medical management for Jehovah's Witnesses*. New York: Watch Tower Bible and Tract Society of New York, 1995.

9. *Re C* High Court of Justice, Family Division: Wall J.; 5 March 1997. The issues of force were also addressed in *Re B (A minor) (Treatment and secure accommodation)* [1997] 1 FCR 618. In that case, the court authorised the use of force to treat a 17 year old drug addict who required a Caesarian section and other medical treatment to preserve her life and health. {Get Ref}

10. Children Act 1989 s25. For explanation, see also *The Children Act guidance and regulations, Volume 4, Residential care*. London: HMSO, 1991: para 8.10. *R v Northampton Juvenile Court ex parte London Borough of Hammersmith and Fulham* [1985] FLR 193.

11. Children Act 1989 s25(7)(a). Children (Secure Accommodation) Regulations 1991 (SI 1991/1505) Regulation 7(1)(a). The health authority or NHS trust providing the accommodation must make the application to court. Children (Secure Accommodation) (No.2) Regulations 1991 (SI 1991/2034).

12. Grubb A. Commentary: Court's inherent jurisdiction (child): Detention and treatment, *Medical Law Review* Summer 1997; 5(2): 227-233.

13. Grubb A. Commentary: Court's inherent jurisdiction (child): Detention and treatment, *Medical Law Review* Summer 1997; 5(2): 227-233.

14. *Re M (A minor) (Medical treatment)*; sub nom *In the matter of the inherent jurisdiction* High Court of Justice, Family Division: Johnson J; 15 July 1999.

15. *Judge orders girl to have heart swap*. Daily Telegraph. 16 July 1999.

16. The Royal College of Nursing. Restraining, Holding Still and Containing Children: Guidance for Good Practice. London; RCN, March 1999.

17. An example of such a policy has been developed by a working party in the Southampton and South West Health District. Southampton Community Health Service Trust & Hampshire County Council Social Services. *Children and adolescents and mental health practice handbook*. October 1996.

Chapter 6: Mental Health Care of Children and Young People

The focus in this chapter is primarily on ethical and practical issues which arise for health professionals providing mental health care for children and young people. Some aspects of mental health law are mentioned. More general legal issues are covered in Chapter 2 and only briefly summarised here.

1. The changing context

The changing dimensions of the problem

The number of children suffering from mental health problems is considerable and appears to be increasing, although it is difficult to make direct statistical comparisons between the prevalence of mental illness within the childhood population at different times. Society is clearly more *aware* of mental health problems in children than in the past, when early indications of illness were often viewed as simply bad behaviour or something that the child would grow out of. Comparisons are also complicated because measurements of prevalence have varied according to factors such as the assessment method used, the definition of what constitutes mental disorder and the particular age group which is the focus of the study. Some studies over the past 20 years have centred on the likely extent of the problem in a particular age group of children; others looked at numbers of children with a particular form of mental disorder. In England, some of the earliest studies were carried out by in the 1960s by Professor Michael Rutter and colleagues, indicating a prevalence of 12 percent of mental health problems among 9-11 year olds. Building on this work, consistently higher rates have subsequently been found in urban as opposed to rural areas. In 1999, the Audit Commission, analysed a number of contemporary studies, including international data, and concluded that about one in five children and adolescents suffer from mental health problems. It concluded that a "diagnosis of psychiatric disorder, according to the established medical diagnostic categories, can be made in between 10 percent and 33 percent of the child population, with a fairly close consensus on a prevalence rate of 20 percent."[1]

The range of disorders

In this chapter, we follow the convention adopted in other reports[2] and use the term 'mental health problem' generically to cover a range of types and severity of psychological and psychiatric disorders in children and young people. Clearly, the widely different types of disorder subsumed under this heading preclude us from mentioning specific treatment options in anything more than a very generalised manner. Management of emotional disorders, such as phobias, is clearly very different to the management of conduct disorders or development disorders, such as autism, or psychotic disorders, such as schizophrenia. Therefore, this chapter is limited to a summary of some of general principles, interspersed with some illustrative case histories.

The extent and type of minors' mental health problems vary according to a number of predisposing factors, including genetic factors and brain damage. In addition, a number of social risk factors have been identified, including abuse within the family, bereavement and homelessness. Recent research has also focussed on understanding why some children exposed to these risk factors develop mental health problems while others in the same situation do not. Three groups of factors appear to protect children and young people from the risks of social and environmental risks:

- Self-esteem, sociability and autonomy;
- Family warmth and absence of discord;
- Social support networks that encourage personal effort and coping.

These factors are particularly relevant to this report where the emphasis throughout is on encouraging those very factors in children's lives. Health professionals have a key role in helping to develop confidence, self esteem and personal autonomy in young patients. Also we have repeatedly emphasised the importance of family involvement and the supportive participation in decision making of other people close to the patient, bearing in mind also the requirements of confidentiality and patient consent to consulting other people.

Changing perceptions of law

In the 1990s, the government recognised that the mental health legislation was "increasingly out of date"[3] and undertook to reform it. The consultation process for that reform has run in parallel with the drafting of this report and therefore this chapter reflects some of the BMA's main views about good practice which we hope will eventually be incorporated into new legislation. Clearly, mental health reform and, in particular, statutory powers for compulsory treatment must also reflect the rights of all citizens under the Human Rights Act 1998. Health professionals must be aware of their legal and ethical obligations in respect of avoiding treatments which may be degrading or inhumane, such as superfluous restriction of patients' movement or natural functions. Lack of privacy and restrictions on visits to the bathroom, for example, are seen by patients as humiliating treatment.[4]

As far as the law is concerned there are fundamentally two ways of approaching mental disorder in minors: either within the Mental Health Act or outside it, through use of the common law and provisions of the Children Act. Much professional and academic debate has focussed on which legal route is likely to be the better one for this particular population of patients. In taking evidence for this report, it certainly appeared to be the case that in the past many health professionals preferred to avoid invoking the Mental Health Act in the case of children and young people. Among the principal reasons for this was the perceived stigma attached to use of the Act and the fact that alternatives exist for children which do not exist for adults, in the form of parental consent and specific treatment orders under the Children Act. Nevertheless, there are indicators of change in that some practitioners who previously avoided the Mental Heath Act for minors, now seem more ready to consider the particular advantages it offers. This changing perception is likely to develop further if the current reform of the Mental Health Act manages to make it more child-centred, since lack of a specific child focus is one of the other criticisms currently made about the legislation.

As is evident from our earlier comments, it is impractical to say that one legal path is necessarily better than the other since much depends on the particular condition and the circumstances of the case. As mentioned above, the term 'mental health problem' covers a very wide range of disorders, from learning disorders and delays in acquiring certain skills to eating disorders, manic depression and drug-induced psychoses. For some of these disorders, use of the Mental Health Act is probably not the best solution. It is seldom used in the management of learning disabled children, for example. Nevertheless, in cases where the child's condition is one for which an adult patient would clearly be treated under the Act, there are good arguments for using it. This issue is discussed further below.

2. Guiding Principles

The relevance of general ethical principles

It is important to emphasise that the same basic ethical principles governing the medical care of minors apply in mental health care as elsewhere. These include the necessity of providing information to young patients in an accessible way, listening to their views and complying, where possible, with their decisions or negotiating with patients to find an acceptable compromise. As in other spheres of treatment, the establishment of a collaborative relationship with the patient is a priority. Therefore the young person must be involved in the discussion even though he or she will not necessarily have the casting vote about what happens. Families should be involved in therapy decisions, wherever possible. Also as with all other treatments, if a young person is judged to lack the competence to make a valid decision about a particular issue, a solution is sought based on an assessment of the patient's best interests. As in all other spheres of treatment, health professionals have an obligation to encourage patients to be involved in weighing up the options and using to the full their own decision-making capacity. The fact that a patient is considered not able to make a valid decision about one aspect of care or treatment does not imply that the same person cannot make other perfectly valid treatment decisions. Just as with other treatments, mental health interventions should be the least invasive possible, the least restrictive of the individual's freedom and should be based on evidence of efficacy. Treatment regimes should aim to separate the child as little as possible from family, friends, school and community contacts. Some of these principles are particularly emphasised in the Mental Health Act Code of Practice.[5]

Guiding principles in Mental Health Act Code of Practice

1. Children should be fully informed about their care. Their views should be sought and taken into account. The impact of the child's wishes on parents (or other people with parental responsibility should always be considered.

2. Any intervention should be the least restrictive possible and segregate the child as little as possible from family, friends, community and school;

3. All children in hospital should receive appropriate education.

Autonomy and treatment planning

The fundamental objective of mental health treatment is to improve the patient's autonomy. Young patients should be involved as much as possible in the planning of their own care and treatment regimes, in conjunction with their families. Clearly, the needs of each patient must be assessed on an individual basis and an approach to treatment must reflect those specific needs. Wherever possible, young patients should be treated in specialised centres, appropriate to their age and their medical condition.

How mental health care differs from other care

Despite the relevance of general ethical principles, it is clear that mental health care differs in some respects from other treatment.

- Risk of social stigma
- Difficulties in ensuring compliance
- Availability of legal methods of compulsion
- Difficulties in ensuring patient confidentiality

Risk of social stigma

Health professionals are very aware of the potential stigma attached to a diagnosis of mental illness. Attention is often drawn to the "reluctance to diagnose psychiatric disorder owing to fears about the adverse effects of medical labelling and stigmatization."[6] As mentioned above, there is still hesitation about invoking the Mental Health Act for minors. Most objections focus on the potentially stigmatising effect. While this cannot be dismissed as a risk, it must be balanced against the benefits accorded to patients by the statutory safeguards in the Act.

Early and accurate diagnosis is essential for early intervention which in turn is crucial to successful treatment. It can be argued that it is the fact of having a "mental disorder" recorded in a patient's notes, or the perception that an individual may be predisposed to dangerous behaviour that are potentially stigmatising rather than the use of the Mental Health Act. If it is accepted that treatment under the Act does not necessarily confer any greater stigma than the fact of involuntary treatment for mental disorder outwith the Act, the advantages of the statutory safeguards inherent in the Act become more obvious.

The issue of stigma should be carefully considered by the health care team in consultation with parents and the child if practicable. Nevertheless, some risks of social stigma remain and create dilemmas for health professionals and families about how best to approach treatment which has to be imposed on patients compulsorily in order to save their lives. The advantages and disadvantages of using the mental health legislation and other alternatives are discussed below.

Difficulty in ensuring compliance

The same ethical principles applicable to other forms of treatment should also be emphasised in relation to mental illness, including to treatment under the mental health legislation. Throughout this report, great emphasis is placed on the ethical importance of seeking *voluntary* and informed patient consent. The patient's consent should always be sought, for example, when the patient is treated under the Mental Health Act. Use of statutory powers does not preclude the implementation of the principles of good practice. When patients properly understand the reason for treatment and the risks of non-compliance, they are more likely to cooperate with the treatment regime. Sensitivity, honesty and trust between doctor and patient are vital to effective cooperation.

Capacity to make a choice

Nevertheless, mutual trust can be hard to establish with patients who have a completely different view of reality to that of the health professionals treating them. Patients with eating disorders, for example, suffer from a condition which not only affects how they see themselves but impinges on their behaviour in a way that can result in death. They may exhibit a more than adequate level of general understanding to grasp the issues but still be hampered in regard to compliance with treatment regimes because of their own distorted perceptions. The Law Commission has drawn attention to the importance of fully evaluating the patient's "capacity to make a choice". The former Master of the Rolls, Lord Donaldson, said in relation to anorexia nervosa that, although a patient may understand the treatment and the consequences of failure to accept it, certain conditions were capable of destroying the patient's ability to make an informed choice, creating a compulsion to refuse treatment or only to accept treatment which is likely to be ineffective. In addition, one effect of poor nutrition is cognitive impairment which reduces the child's ability to make rational decisions.[7]Among the ethical and practical dilemmas facing health professionals treating this group of patients is when to judge that the collaborative approach can no longer be sustained. Clearly, the objective is always to maintain a relationship based on patient consent and negotiation, even though this may entail allowing the patient to take some health risks. At some point, however, the risks become untenable and health professionals have to take over responsibility.

Case example

X was a competent and articulate young woman, suffering from an eating disorder. The option of in-patient treatment was discussed with X and her family, who were all in agreement that it was essential to her longterm health. Nevertheless, X wished to postpone admission to the unit until she had reached a particular low weight goal. She felt that if she were able to achieve this low weight, even temporarily, it would enable her to overcome her weight obsession and put it behind her. The health team and X's family agreed to allow her to try this option as long as she agreed to cooperate with treatment as soon as she reached that weight or sooner if her health seemed jeopardised. Initially, therefore, the health team were in the paradoxical position of supporting X in her attempt to lose more weight. Before she reached her goal, X became increasingly ill and after discussion agreed to be admitted for in-patient care once she had reached a compromise weight which was higher than her original goal. Although the health team discussed the various options for overruling X's efforts to postpone treatment, including use of the Mental Health Act, it was agreed that until the health risks for X became too great they would attempt to maintain supervision and treatment on a voluntary basis, even though this required frequent re-negotiation.

Fundamental differences in perception between therapist and patient are obviously not restricted to cases of eating disorders. Adolescents who are severely mentally ill with other conditions may equally refuse treatment because they do not believe themselves to be ill. Negotiation with the patient is equally important in such cases but, similarly, decisions have to be made regarding the point at which the collaborative effort can no longer be sustained. Families are also anxious that they should have an opportunity of voicing their concerns and suggestions for solutions. Good communication between the health team and people close to the patient should help avoid situations in which young patients with a mental disorder might be given autonomy in such a way as to incur harm to themselves and to other people

The case of M

At the age of 5, M was said to be hyperactive. Her parents coped with this by a programme of sports activities rather than medication, which seemed to work well until M entered her teenage years. M was 14 when she was eventually taken into local authority care in 1989. Prior to this, she had demonstrated increasingly unpredictable, disruptive behaviour. At school, she had been prone to bouts of violence and aggression. She continued to be increasingly angry and violent. As there had been a history of behaviour problems in other family members, M's mother asked for various tests to be carried out to ascertain whether there was a physiological cause. M refused to comply with such tests. Her wishes were respected and the tests were not done. She also refused to return home when given the option. M's mother believed that M was being given too much power to manipulate those around her. In her mother's words, M "changed solicitors, social workers, key workers, as and when she wanted... M learned about sniffing, cutting herself, her rights in law...She hospitalised herself and many members of the public...(she) soon learned that as a minor, and particularly as a girl, she would rarely get into serious trouble for assault, criminal damage, violence." Despite a general reluctance for criminal charges against M to be instigated, by the age of 17 she was in Holloway prison. Eventually, M was sectioned under the Mental Health Act and detained in a secure psychiatric hospital. The EEG which her mother had requested years previously was eventually done and revealed an irregularity in M's brain. A year later, M was released. She registered with a doctor as a temporary patient and requested five days' prescription of Promazine, Nitrazepam and Procyclidine which she received. She ingested most of these drugs the same day. Two weeks later, her body was found next to a motorway. Her mother published an article about the case, arguing that M had been too much power and because of her illness lacked the ability to make decisions in her own interests. Balancing the right of self determination, M's mother argued for the right for young people like M to be protected from themselves.[8]

The ethics of involuntary treatment

From an ethical perspective, a particularly difficult aspect of mental health care is the concept of compulsion or coercion which is often (but not invariably) associated with this form of treatment. The fact that the law permits the use of compulsion for a particular sphere of medical treatment seems potentially to undermine the sense of balance in the relationship. For various reasons - to "protect" them or because their abilities are under-estimated - children may feel marginalised in the decisions about their treatment. The legal availability of compulsion in some circumstances may reinforce young patients' sense of power resting with health professionals and their own lack of choice.

On the other hand, an advantage of using the Mental Health Act to abridge their autonomy is that, in the strict sense, it does not infantilise the patient. The Act is not age specific and applies equally to adult patients as to minors. It also grants some rights to detained patients to balance the reduction in autonomy. Minors have the same rights under the Act as adults with similar medical conditions.

In the past, the availability of legal powers of compulsion may also have been mis-perceived by some health professionals as a reason for not providing patients with relevant information and seeking their consent. Involuntary treatment is only ethically justified when it is intended to protect the health interests of a person who cannot decide about that for themselves or where the individual's condition might result in others being harmed.

Difficulties in maintaining confidentiality

Because of the potentially stigmatising effect of treatment for a mental disorder, patient confidentiality is particularly important in this area but it is also an area of practice where confidentiality seems particularly hard to protect. Some of the practical difficulties arise because some forms of therapy, involving competent young people are family-based and designed to include family therapy or parental counselling. Treatment may involve encouraging patients to air with their parents important issues which they are exploring with their key workers. Obviously, patients need to be able to do this at their own pace.

The Mental Health Act Code of Practice (s31.21) emphasises that "children's rights to confidentiality should be strictly observed. It is important that all professionals have a clear understanding of their obligations of confidentiality to children and that any limits to such an obligation are made clear to a child who has the capacity to understand them."[9]

In the case of mental illness, exceptional circumstances may arise where it becomes necessary to disclose information without consent either to protect the patient or other people from serious harm. Disclosure in such cases should follow the same principles as non-consensual disclosure in other cases and where possible, the patient should be informed in advance of the need to breach confidentiality and why. (See Chapter 3). Confidentiality should only generally be breached contrary to the patient's wishes when issues of safety arise. Nevertheless, as in all other areas of care, good liaison and communication between different agencies is essential. A range of professionals may need to be kept informed following the child's discharge from inpatient care, including the GP, local psychiatric service, social services and schools. Patients may be particularly sensitive about how information about their mental health is shared and more anxious about this than they would be for a purely physical illness. Therefore, they need to know how information will be shared.

3. The role of consent and the law in mental health care

Consent in mental health care is the same in most respects as in other spheres of care. The general legal principles in respect of consent and refusal are discussed in Chapter 2.

Treatment of a child who lacks competence: As with other treatments, a child who is not capable of making his or her own decisions can usually be treated with the consent of a parent, or another person with parental responsibility. Legal issues such as the use of detention and restraint, under the principle of "necessity" for people who lack capacity are also covered in Chapter 2.

Consent by a competent child: The ideal treatment plan involves the voluntary consent of the child or young person. The fact that a patient suffers from a mental disorder does not necessarily mean that he or she cannot give valid consent to treatment. Health professionals have an ethical duty to work to enhance the patient's competence to participate in decision making. (See Chapter 3)

Refusal by a competent child: In some cases, it may be possible to negotiate an acceptable treatment compromise when a competent child refuses the proposed option. Children or young people under 18 cannot legally override a consent to treatment given on their behalf by anyone who has parental responsibility. In effect, this means not only consent by parents and guardians but also a local authority with the benefit of a care order. When a competent child refuses treatment, parental consent is often the next option. Even though a refusal by a competent child or young person lacks legal weight, the fact of such a refusal is still an important consideration in making clinical judgements. Although there are no hard and fast rules, health professionals are increasingly reluctant to impose invasive treatment, even with parental consent, on competent minors who resolutely and consistently refuse it. In such circumstances, legal advice should be sought and some cases may need court review. This is more likely if the treatment is controversial in some way or the long-term benefits of imposing it are in doubt. (See Chapter 2)

In addition to refusing treatment generally, in cases involving emergency protection orders, child assessment orders, interim care orders and full supervision orders, the Children Act also specifically provides for a child to be able to refuse assessment or examination or treatment. In such a situation, however, the High Court can still override the Child's refusal and again legal advice should be sought. (The distinction between the powers available under the Children Act, wardship and the inherent jurisdiction of the High Court is explained in Chapter 2).

Authorisation by a court: Courts generally only need to be involved if the proposed procedure is controversial in some way or when consent is unavailable from either the patient or a person with parental responsibility. Where an alternative statutory mechanism exists - such as the Mental Health Act or the Children Act - to authorise treatment, courts are reluctant to become involved. In some cases[10] where courts have been asked to intervene to authorise treatment of young people, this could equally have been provided under the Mental Health Act. Legal experts argue that where statutory provisions to authorise treatment already exist, these should be used in preference to seeking court authorisation.

The Mental Health Act Code of Practice identifies some circumstances in which the courts are particularly likely to be consulted:

- in the case of an under-16 year old who lacks competence and no person with parental authority can be found or that person also lacks the mental capacity to make the decision on the child's behalf;
- where a person with parental responsibility does not appear to be acting in the child's best interests.

Use of Statutory provisions: In law, there are three overlapping legal frameworks for authorising mental health care of minors: the Children Act, the Common law and the Mental Health Act. The interrelationships between the two statutes and the Common Law are complex but, as mentioned above, the really fundamental choice is whether to work within the Mental

Health Act or outside it. Health professionals working in this field need to be familiar with the limits and benefits of both.

There has been considerable debate about which option is most appropriate. During its review of child and adolescent mental health services in the mid-1990s, the NHS Advisory Service noted the anxieties of health professionals about identifying the most appropriate legal framework in circumstances when it was necessary to detain a minor and require him or her to undergo medical treatment. The Advisory Service noted that the "choice is not always easy... Given the complex relationship between the two pieces of legislation and evolving relevant case law, it is not possible to provide other than general pointers that could usefully be taken into account by professionals when deciding which route to take."[11]

In fact, both offer some advantages and some drawbacks. Choices have to be made on the basis of what best suits the individual child and the type of mental disorder from which the child suffers. What is certainly problematic, however, is that at present, whether a child is detained under the mental health legislation or treated under the Children Act appears to be "somewhat arbitrary". Health professionals and families need to consider which seems most applicable to the circumstances of the case. (The Children Act is discussed in more detail in Chapter 2).

The Children Act:

It is applicable to children who do not have a diagnosable psychiatric illness but could benefit from admission to a child psychiatric unit.

Under the Act, a *guardian ad litem* is appointed to ascertain the child's wishes.

The *guardian ad litem* makes recommendations about the child's best interests.

Assessment is carried out according to a broad welfare checklist

It is perceived by some as potentially less stigmatising than the Mental Health Act.

It does not specifically address mental disorder, does not provide specific powers to enforce treatment nor does it provide safeguards for the rights of the detained patient.

It is seen as particularly appropriate for younger children (under-12s)

The main strengths of the Children Act in this context are seen in the way it particularly focuses attention on the wishes and needs of children. The *guardian ad litem* has the task of considering all the relevant factors in the child's case, including the child's level of maturity. This arguably provides a broader vision of the individual's circumstances. It may appear less stigmatising as it does not specifically refer to mental illness but its use may be seen as reflecting social and family failure. The most lasting powers under the Children Act are consequent upon court decisions while the exercise of powers afforded by the Mental Health Act is the consequence of professional judgement and does not involve court review.

In assessing the legal framework within which an individual child should be treated, the scope of the treatment needs to be taken into account. Treatment of minors may involve both detention in a secure environment and administration of medical treatment. Unlike the Mental health Act, the Children Act does not specifically provide for a child's decision about treatment to be overridden and consent is such cases is usually sought from parents. If there is a dispute, the court can make an order specifying the steps to be taken. Although there is a range of differing views among health professionals, many see this Act as more appropriate for younger children and particularly for treatment of conditions like eating disorders in under-12s. The Children Act also gives Gillick-competent minors the right to refuse medical or psychiatric examination and the extent of the child's scope to refuse was examined in the case of Welsh legal case of 1992. (Wider aspects of this case are discussed in Chapter 2)

South Glamorgan County Council v B and W.

In 1989, at the age of 12, A was referred to an adolescent psychiatric unit because of persistent absence from school. In 1990, her father gave consent for A to go into care. After discharge, A was the subject of a series of interim care orders which her family eventually opposed. Although judged not to have any psychiatric abnormality A continued to miss school. At 14, she began to show domineering behaviour, became obsessive and barricaded herself in a room. This continued for 11 months. A child psychiatrist found her coherent but uncooperative and recommended that A be removed and looked after in an adolescent psychiatric unit. This should be done, he said, not under the Mental Health Act but "as a child clearly beyond parental control, the Children Act is a more appropriate option". A second psychiatrist visited A, concluded that her mental health was seriously at risk and recommended that A be received into a psychiatric unit "via the Mental Health Act or through the court". A threatened suicide. Social workers concluded her condition was not suitable for an order to be made under the Mental Health Act and a third psychiatrist concluded she was not mentally ill. The guardian ad litem reported that A was beyond the control of her family and recommended a care order under the Children Act. Her father strongly opposed her being removed by force but her psychiatrist insisted she needed in-patient assessment. The local authority began proceedings which made A subject to an interim care order under the Children Act. It also asked the court for leave to remove A to a psychiatric assessment centre, using reasonable force and for A to be restrained from absconding from the unit. These requests were beyond the powers of the interim care order under the Children Act. The family's lawyer argued that a Gillick competent child (as A was judged to be) could refuse psychiatric assessment under the Children Act. The judge concluded that when other remedies within the Children Act had been exhausted, the courts could still override the refusal of a competent child.

The Mental Health Act

Arguably, if mental illness is the defining issue, there is no strong reason why it should be handled differently in children to the way it is handled in adults. Although the Act is not child-centred, it gives minors the same rights as adults. In the past, the Mental Health Act was rarely used for people under the age of 18[12] but this appears to be changing and the Act is sometimes used for treatment of eating disorders in older children as well as for other psychiatric conditions in this age group.

Summary of points concerning the Mental Health Act[13]:

Authorises mental health treatment of patients of any age.

Generally perceived as more appropriate for teenagers than for younger children.

Seen as potentially appropriate for teenagers with sufficient understanding to make a decision (although it may be necessary to override that decision)

May be appropriate if treatment involves the use of medication for an extended period, or ECT (see below);

Should be considered if the use of force is likely to be necessary to administer the treatment;

Allows patients to be legally detained for treatment, in the interests of their own health.

It is not necessary to demonstrate a risk to their own or other people's safety.

Evidence must suggest that patients' mental health will deteriorate without treatment.

It is seen as unsuitable for patients who do not require in-patient care.

Patients must have a diagnosable "mental disorder" but this is defined very widely in the Act.

The Act incorporates a number of safeguards for patients.

Perceived as potentially stigmatising for patients.

It is seen as unsuitable for patients who do not require in-patient care, or who require treatment for a physical disorder, unconnected with their mental disorder. The courts, however, have given a wide interpretation to "treatment for mental disorder". For example, it has been accepted that feeding without the patient's consent may form part of a programme of treatment for a mental disorder. Thus where a teenager refuses a life-saving treatment such as naso-gastric nutrition, this could be provided under the Act. In 1997, the Mental Health Act Commission published specific guidance on the treatment of anorexia nervosa under the Mental Health Act.

Summary of Guidance on Treatment of Anorexia under the Mental Health Act

- Compulsory measures are often unnecessary but given the significant mortality associated with anorexia, clinicians may use the Act if the patient's life or health is at risk;
- Anorexia can fit within the definition of mental disorder in the Act;
- It is for health professionals to decide whether a particular patient should be detained under the Act and under which section;
- Where a patient is detained for assessment or treatment, the patient's consent should always be sought;
- The patient must be given sufficient information to understand the effects and risks of treatment and the alternatives;

- Treatment for a physical condition can only be given if clearly connected to the patient's mental disorder;
- Courts have accepted that feeding a patient by artificial means can be an integral part of treatment of anorexia.

The legislation provides a legal justification for both detention in hospital and compulsory treatment It also gives children the same safeguards as are considered appropriate for adults in the same position, including restrictions on the continued use of drug treatments for detained patients without consent (see below) and an appeals and review system. Use of the Act is strongly advocated by some legal experts[14] who argue that young people are more likely to act responsibly if treated like adults. Also that young people who are compulsorily admitted for treatment in a psychiatric setting should be given the same rights as adults in that situation.

The case of R

R was 15 years and 10 months old in 1991. She had a history of family problems and had been on the local authority's at risk register. R was received into voluntary care after a fight with her father. While in care, her mental health deteriorated and she began to have visual and auditory hallucinations. Her behaviour became more disturbed and there were worries that R might attempt suicide. A psychiatrist who examined R after an episode of increasingly paranoid and disturbed behaviour considered that R was ill enough to be sectioned under the Mental Health Act. She subsequently absconded, returned to her parent's home and ran amok causing serious damage. She attacked her father with a hammer. The local authority obtained a place of safety order and a care order and placed R in an adolescent psychiatric unit where she was sedated with her consent. Concern grew, however, that R should be given compulsory medication because she was becoming increasingly defiant. Although R had previously given apparent consent to sedation, she now said that she only consented because she had no choice and if she refused, she would be injected anyway. R was made a ward of court. The consultant treating R then applied for permission from the local authority to administer anti-psychotic drugs as R had become extremely paranoid and hostile. R herself then telephoned the social services night duty department alleging that the unit were trying to give her drugs which she did not need against her will. The telephone call lasted three hours and the social worker concluded that R sounded rational and lucid and that she was not sectionable under the Mental Health Act. Therefore the local authority refused to give permission for the anti-psychotic drugs. The case eventually went to the Appeal Court where Justice Farquharson said that it was difficult to apply the Gillick competence criteria to a case such as this where the child's capacity fluctuated under the impact of mental illness. The court ruled that R's refusal could be overridden because the primary duty of the court was to ensure her welfare and the relevance of whether she possessed mental capacity, according to the Gillick criteria, was seen as not determinative in that decision.[15]

In deciding which legal route to take, health professionals need to:

- have a good understanding of the relevant legal provisions;
- have access to expert legal advice;
- keep in mind the importance of ensuring that the child's care is managed with clarity, consistency and within a recognisable framework;
- attempt to use the least stigmatising and restrictive option that is consistent with the care and treatment options for that patient.

The specific purpose of the intervention needs to be evaluated. A number of relevant factors need to be taken into account, such as the length of time the child is likely to require treatment and detention and the seriousness of the illness. The balance must be weighed between the need for containment and the need for medical treatment of a mental disorder.

4. Practical aspects of mental health care

Working with the patient's desire for control

An important area of child mental health care concerns treatment of children with eating disorders. Increasingly, anorexia nervosa, for example, is recognised as occurring in children as young as eight. "A key feature of these disorders is the issue of control and patients will report an extreme fear of losing control of their bodies... Bearing this in mind, successful treatment needs to help such children regain control over their lives". In practical terms, this raises many difficulties when the patient and the health team have differing views about treatment.

Multi-agency care: As with other types of care and treatment mentioned in this report, children's mental health services must be child-centred and aimed, where possible, at supporting children within their own families. Assessment of a child's needs should include consideration of both health and social care needs and also the needs of the family as a whole. Children and young people with serious emotional or mental health problems may be referred to any of a number of agencies or professionals but one person must be identified at an early stage as responsible for co-ordinating assessment and care planning.

Confidentiality and communication: A multi-agency response means that various services need to maintain contact and good working relationships concerning the provision of different facets of care. Children and their families should be given as much information as possible about the range and scope of services available to them in their locality. The decision about which agency co-ordinates assessment for services depends on the circumstances of the individual referral and the wishes of the patients and their parents or carers. Clearly, effective communication between agencies is essential but must be balanced with awareness of the young person's rights of confidentiality. (Confidentiality is discussed in detail in chapter 3).

Confidentiality and continuity of care: Concern has previously been expressed by expert groups[16] about practices such as the use of psychiatric health records made on children being passed, without explicit consent, to adult mental health services if patients, previously seen as children, contact that service later in life. The importance of awareness of a patient's past history and of continuity of care are issues that need to be balanced with the individual's right to privacy and to control information about themselves, wherever possible.

Appropriate accommodation: Children subject to compulsory care and treatment should be treated within an environment that is appropriate to their age and clinical need. At present, however, insufficient specialist units exist for young people suffering from conditions such as eating disorders. Young people with mental illness should be treated within adolescent psychiatric units. Paediatric wards and adult psychiatric facilities are not the best environments for treatment of this patient group.

Secure accommodation:In England and Wales, detention of children and young people in secure accommodation is covered by the Children Act 1989. Court authorisation is required to keep a child or young person in secure accommodation for more than 72 hours in any period of 28 days. Authorisation may not be for more than three months in the first instance, and six months at each renewal. The same rules apply to children if they are accommodated by health authorities, NHS Trusts and local education authorities, residential care homes, nursing homes and mental nursing homes. These provisions do not apply to children detained under the Mental Health Act, or certain children who are the subject of criminal proceedings. But otherwise, it is clear that court approval is necessary if a child is to be placed in a locked ward in a mental hospital, a regional secure unit, or other secure facility. A secure accommodation order does not authorise the child's treatment, and a separate legal justification must be found for any treatment.

Specialist mental health resources in secure accommodation: Residence in a secure system means a first opportunity for many young people to receive therapy and education in a protected setting. Such placements can provide the foundations for further development provided through after-care by out-reach teams once the young person returns home. At present, however, it seems that many of these opportunities are lost. Mental health experts have called for the development of specific specialist resources which can offer consultation and training to institutions where young people are securely held and to local community teams so that they can continue with effective interventions. This is a recommendation which the BMA supports.

Restriction of liberty/restraint: General guidance and discussion of the ethical issues which arise in relation to restraint and restriction of liberty are covered in Chapter 2. Only a brief mention is made here of the way in which use of restraint is particularly relevant to mental health care. Restraint, if used in a prolonged or repeated way may amount to de facto detention, in which case, court approval is likely to be required unless a child is formally detained under the Mental Health Act. If restraint needs to be prolonged or repeated, urgent advice needs to be sought about the legality of effectively detaining a child contrary to his or her will. Consideration may need to be given to the question of formal detention under the mental health legislation and a view may need to be sought from social services to that effect.

Grey areas concerning restraint: The Department of Health Guidance acknowledges that there may be grey areas as to what constitutes a restriction of liberty. It advises that any practice or measure which prevents a child from leaving a room or building of his or her own free will may be deemed by the court to constitute a restriction of liberty. One case that was taken to court, for example, concerned a twelve year old child who was kept in an open adult ward in a nightdress, with her clothes locked in a cupboard. While it is clear that locking children in a room or part of a building, to prevent them leaving voluntarily is caught by the statutory definition, other practices, which place restrictions on freedom of mobility are not so clear cut. A variety of tactics which amount to restrictions on children's freedom of movement have been used in adolescent psychiatric units. The BMA supports Department of Health advice that in any case of doubt as to what constitutes acceptable restriction, advice should be sought and an application may need to be made to a court to determine the issue.

5. Safeguards for particular medical treatments

Certain psychiatric treatments require special safeguards when proposed for any patient. Although the mental health legislation provides a system of statutory safeguards, some of these apply only to patients who have been formally detained. Clearly it is desirable that child patients who are detained under other legislation or *de facto* detained should be entitled to the same degree of protection, regardless of their legal status.

Drug treatments

Intramuscular injections of antipsychotic drugs carry significant health risks, particularly when given to a struggling patient. There is also a danger that medication may become a means to control difficult behavior, rather than treatment . The Mental Health Act provides safeguards for children detained under the Act. Medication for a mental illness may be given without the child's consent for a period of three months, beginning when medication is first administered. After three months, apart from emergencies, medication can only routinely be given in limited circumstances. One option is for the patient to consent to receiving treatment. Alternatively, a second independent doctor must certify that the patient is either not capable of consenting validly or certify that although the patient has refused, the treatment should be given because it will alleviate or prevent a deterioration of the patient's condition, Even where a child patient has not been formally detained, it would be good practice to obtain a second opinion if the patient refuses.

Electroconvulsive Therapy (ECT)

The use of ECT for child patients is highly controversial, and there have been calls for its prohibition. Nevertheless, it was reported in 1994 that a survey of child and adolescent units found 60 cases of young people receiving ECT over the previous decade. The safeguard previously mentioned for drug treatment also applies to this category of treatment so that (except in emergency) the provision of ECT to a detained child requires the child's valid consent or the certificate of a second opinion appointed doctor. If it is thought necessary to administer ECT to a child who is an informal patient, legal advice should be sought and the possibility of seeking court approval should be considered.

6. Timely access to services

One of the relatively new principles beginning to emerge in lists of ethical principles is that of reciprocity. This embodies the concept that patients have a positive right to the services they need in order to comply with their care programme. Traditionally, mental health services have frequently been marginalised, making it difficult sometimes for patients to obtain timely access to the care they need. For young people in particular, difficulty in accessing appropriate mental health support services can have very profound consequences for their future development. Research published in 1999[17], for example, drew attention to the fact that in the UK, children and young people constitute a quarter of all known criminal offenders. The report published by the National Association for the Care and Resettlement of Offenders (NACRO) indicated that children and young people suffering from poor health, including those with some types of mental health problems, were more likely to get drawn into crime than their peers. While acknowledging that the link between poor health and crime was a complex one, the report concluded that the factors which indicate a young person is at risk of offending overlap to a significant degree with those which predispose young people to adopt unhealthy lifestyles. Repeated surveys[18] have shown that a large proportion of young offenders come into prison from unstable living conditions and many have experienced homelessness, which makes access to medical care particularly difficult.

It would be invidious to imply that poor mental health is necessarily linked to behavioral problems and law breaking. But it does seem that young people who are drawn into the criminal justice system or demonstrate persistent anti-social behavior often do suffer from some mental health problems, for which they experience difficulty in obtaining appropriate care and treatment. The prevalence of psychosocial disorders in the young is growing[19] but there also appears to be "an increasing tendency to criminalise difficult behavior in the young". Experts consider that the combination of both trends means that mental health resources have to deal with a wide variety of problems, perpetuating the present thin spread of available expertise. Various commentators have also drawn attention to the fact that once involved with the criminal justice system, focus on "their offending behavior tends to take precedence over developmental and mental health issues"[20] which may be ignored in a way that problems with physical health would not be, in the same situation.

In 1996, the Audit Commission considered some of the links between health and the cycle of anti-social behavior in children and recommended that mental health professionals focus more on "indirect work, supporting health visitors, family centres and voluntary groups when they are dealing with children whose behavior is difficult."[21] Links were drawn between some forms of anti-social behavior and the experience of emotional, physical or sexual abuse. Children who have experienced such problems are more likely to be caught up in the criminal justice system or be taken into local authority care where they manifest a common range of needs, frequently including emotional and mental health difficulties. Subsequent research by NACRO has shown, however, that the full potential for considering the impact of poor health, particularly poor mental health, upon youth crime had yet to be fully explored. Until relatively recently, for example, awareness of adverse mental health in children was limited to experts in this field. Children were not widely perceived as potentially suffering from mental disorders. Yet a review in 1997 by the Chief Inspector of Prisons, suggested that over half of all young males on remand and over 30% of those sentenced suffered from a diagnosable mental disorder. Clearly, this constitutes a dramatic over-representation within the prison system of young people suffering from poor mental health, which needs to be addressed by careful targeting of services.

Good practice guidance

The Royal College of Psychiatrists is among the bodies establishing good practice guidance, including the following points.

Good practice should be based on:

- evidence of efficacy;
- equitable access;
- service acceptability to enable optimal patient compliance with treatment;
- maintenance of staff skills and morale;
- planned and agreed prioritisation of cases;
- holistic management of the child and awareness of relevant contextual factors;
- maximum participation of the child in decisions with full consideration being given to the child's wishes;
- optimal use of resources.

7. Appeals and Complaints

As in all other sphere of medical practice, patients and their families need to be aware of how they can take forward an appeal or complaint. They must also be assured that their decision to do either will not adversely affect the continued provision of services. There are some specific measures relating to mental health care, such as a right of appeal by detained patients to a Mental Health Review Tribunal or a Manager's Review. It is the duty of the hospital or Trust to ensure that patients and their families are aware of their rights in relation to these hearings. A child or young person has the same rights as other detained patients to a hearing by a Mental Health Review Tribunal.

Patients and their families should also be aware of local mechanisms for registering any other type of complaint about the care or services provided. Complaints should be dealt with as promptly as possible by the manager or clinician in charge of the patient's care. When complaints cannot be resolved locally, patients need to have information about how to take them forward.

Summary of principles relevant to mental health care

- care should be consensual wherever possible and respect patient autonomy;
- minors' views should always be taken into account;
- the provision of information and effective communication should be emphasised;
- all patients should be as involved as possible in developing their own care plan;
- care and treatment should be non-discriminatory and respect diversity;
- care should be provided in the least restrictive setting possible;
- treatment should involve the least possible segregation from family, friends, school;
- where possible, families should be involved in decisions about therapy;
- where patients are required to comply with a care regime, they must be provided with all the services specified in their care plan;
- informal care should be considered before recourse to compulsory care;
- treatment should be evidence based.

1. Audit Commission, as above.

2. This, for example, is the approach adopted in the 1999 Audit Commission report mentioned above.

3. Foreword by Health Minister, Frank Dobson, to the 1999 edition of the Mental Health Act Code of Practice, HMSO.

4. BMJ (1995) 311, 635-636.

5. 1999, Mental health Act Code of Practice, HMSO.

6 Kurtz A, Thornes R, Bailey S, Children in the criminal justice and secure care systems: how their mental health needs are met, Journal of Adolescence 1998, 21, 543-553.

7. Strauss J, Ryan R M, (1988) Cognitive dysfunction in eating disorders, International Journal of Eating Disorders, 7; 19-27.

8. Article by Morgan S, At Risk from Themselves, YoungMinds Magazine, April 1996.

9. 1999 edition of the Mental Health Act Code of Practice, HMSO.

10 *Re R* (above) and *Re W* [1993] 1 FLR 1

11. Add refs

12 See for example, Black, Wolkind and Harris Hendricks, *Child Psychiatry and the Law* (2nd ed, 1991), p. 83.

13. Details of the Mental Health Act 1983 are likely to change as a result of lengthy government consultations and the recommendations of a government-appointed scoping group.

14. Freeman M (1992). Removing rights from adolescents, Adoption and Fostering, 17(1), 14-19.

15. The case of R is also discussed in Chapter 2.

16 Dixon R, Children and Adolescents and Mental Health: Practice Handbook, 1996.

17 NACRO report, Children, Health and Crime, (1999) London.

18 See, for example, Cavadino P, co-author of NACRO report, Going Straight Home, published December 1999.

19 Rutter M T & Smith D J (eds) (1995) Psychosocial Disorders in young people, Chichester, John Wiley & sons.

20 Hindle D, Leheup R, Rethnking Provisoin for Delinquents, YoungMinds Magasine, July/August 1998.

21 Audit Commission, Misspent Youth, (1996).

Chapter 7: Sensitive Or Controversial Procedures

In this chapter, consent and refusal are considered in the context of medical procedures which are either very sensitive or controversial. Treatment may fall into this category for a number of reasons, some of which are to do with the nature of the procedure itself and some arise because the patient is a child and is not sufficiently mature to make a personal decision. Some treatments, such as contraception, abortion and treatment for sexually transmitted disease, are rightly seen as sensitive and very personal matters for any person but raise particular concerns when the patient is a minor. Whilst all patients facing difficult treatment decisions need information and support, additional safeguards are needed when children and young people are involved.

This chapter begins by considering the ethical principles common to many types of sensitive or controversial treatment before moving on to consider a number of specific examples of procedures that fall into that category. It does not provide a comprehensive list of all such procedures but aims is to address the issues health professionals most frequently face and set out some general principles which can be applied.

1. General ethical issues

a) Consent to procedures for the benefit of others

Some procedures are controversial because they expose the patient to risk of harm for the benefit of other people. Informed and competent adults may decide to risk or sacrifice some aspect of their own physical health in order to achieve some other goal which is important to them. In order to help someone else, they may donate bone marrow or a kidney or volunteer for invasive research, knowing the risks to their own health. They may undergo genetic testing in order to help a relative even though this gives them information about themselves that they would prefer not to know. The role of health professionals here is to provide accurate information, minimise the risks as far as possible and verify that the individual is not subjected to unacceptable pressure. Where the patient is a child, or young person, however, health professionals have a responsibility to ensure that that person is not foreseeably exposed to more than minimal health risks in order to benefit other people. (While there is no universally agreed definition of "minimal risk", some criteria for assessing risk are given at the end of this chapter).

It would be ethically unsound to assume that, if they were able to express an opinion, young children, unconscious patients and mentally incompetent adults would automatically volunteer for physical pain or discomfort in order to help someone else. It can be argued, however, that it would also be wrong to assume that all individuals who cannot consent lack altruism and would not wish to help others, if they could do so at little inconvenience or risk to themselves. Therefore, while minors should not be exposed to pain or serious risk, it may be acceptable for them to undertake some procedures to benefit other people, as long as they are not opposed to doing so nor likely to suffer harm. For controversial procedures such as this, parental consent is generally sought, in addition to the young person's own consent.

(There are some exceptions, see section on family planning and abortion below.)

Parental consent

Clearly, babies and young children are unable to give their views. As is discussed in Chapter 2, the law permits a person with parental responsibility to consent to medical treatment on behalf of a young child but this does not automatically extend to procedures which are not in the child's best interests. This is made clear in various guidelines, including legal guidance published by the Department of Health.

"*Those acting for the child can only legally give their consent provided that the intervention is for the benefit of the child. If they are responsible for allowing the child to be subjected to any risk (other than one so insignificant as to be negligible) which is not for the benefit of that child, it could be said they were acting illegally.*"[1]

In practice, however, a very broad definition of best interests is used. Parents are permitted, for example, to consent to the donation of bone marrow by a child to benefit a sibling. While this is not physically in the interests of the child, it is argued that it would be in the child's emotional and psychological interests to save another family member (see below). Parents are also permitted to consent to blood tests on babies for research purposes. Although of no direct benefit to the child, it is justified on the ground that there is no harm to the child and there may potentially be considerable benefit to society arising from the research. Thus, while emphasising the concept of "best interests", it is clear that society is somewhat ambivalent about it, particularly if upholding the "best interests" standard risks foregoing some other goal that society sees as important. Thus, parents are allowed to impose some risks on their children in such cases, as long as that risk is below a certain threshold (usually categorised as 'minimal') and the expected benefit to others, or to society as a whole, seems to justify the risk. The BMA advises, however, that for any procedure which is not in the child's own interest, and involves more than minimal risk, expert legal opinion should be sought on the limits of parental consent.

b) Assessing "best interests"

Whilst the concept of "best interests", as discussed in chapter 1, is the paramount criterion in decision making with children and young people, this clearly does not prevent young children from undergoing procedures or testing for the benefit of other people. All patients' interests are multi-faceted. The various physical, emotional, social and psychological needs of the whole person need to be recognised. Children's best interests are often linked to the welfare of the people who care for them. Therefore non-therapeutic interventions can sometimes be justified as being in the overall human interests (although not in the narrow physical interests) of the donor or person being tested.

As is emphasized throughout the report, apart from babies and the very young, children usually can express clear preferences and desires about what they would like to happen. Because of their dependent status within the family, however, and their desire to please adults, they are also particularly vulnerable to influence and pressure. The aim, therefore, must be to achieve balance and proportionality between giving children the scope to act altruistically while avoiding the risk of them being used as a means to satisfy other people's goals. Donation of blood or tissue, for example, obviously does not benefit the donor physically but may provide significant emotional or psychological benefit if it is used to help a close relative. On the other hand, consideration must also be given to the potential resentment experienced by healthy children who feel continually required to sacrifice their own preferences for the good of a sick sibling who is the focus of family attention.

The BMA takes the view that in some cases, interventions that are not clearly in a young child's physical interest may be ethically acceptable if they do not expose the child to more than minimal risk. Such interventions are more likely to be ethically acceptable if it is clear that most competent people, if asked, would generally be willing to comply in similar circumstances.[2] Clearly, where the young person is competent to make a decision, his or her views should generally be respected. As mentioned above, efforts must be made to ensure that consent in such situations is not the result of undue emotional pressure from others.

c) The concept of "acceptable risk"

Assessment of risk is an important part of decision making in all forms of health care. All advances in the clinical care of children are obtained by trying new procedures or modifying standard processes where evidence indicates that this is likely to have the most successful outcome. The family and the health care team should give careful consideration to all the facts. The degree of risk incurred is one of the issues upon which families most seek reassurance. Despite the existence of some guidelines, no generally applicable categorisation of "risk" has yet been achieved[3] and the question of significant risk needs to be discussed on a case by case basis.

d) Confidentiality

The general principle of confidentiality is discussed in detail in Chapter 3 where it is emphasised that children and young people have the same rights as other patients but that no-one has an absolute right of confidentiality. The General Medical Council advises that disclosure without consent may be justified where the patient does not have sufficient understanding to appreciate what the advice or treatment being sought may involve, cannot be persuaded to involve an appropriate person in the consultation, and where it would, in the doctor's belief, be *essential to the best medical interests* of the patient.

In addition, confidentiality must be balanced against society's interests in protecting vulnerable people from serious harm. Thus, for example, a breach of confidentiality may be justified if the patient's silence puts others at risk and the doctor cannot persuade the patient to make a voluntary disclosure. In such cases, it is important for health professionals to provide counselling with a view to preparing the patient to agree, when ready, to confidentiality being relaxed. This task assumes greater urgency if the patient, siblings or other minors continue to be in a situation of risk so that in some cases, the patient has tobe told that confidentiality cannot be preserved. Wherever possible, disclosure should not be made without first discussing it with the patient whose cooperation is sought.

Health professionals may suspect that a minor is being exploited, abused or neglected. It must be made clear to the patient that secrecy cannot be guaranteed when there is a risk of harm to any person. With supportive counselling, young patients are often willing to agree to disclosure. The task of encouraging them to do so assumes greater urgency if this child or other children remain at risk so that in some cases, doctors have to breach confidentiality without consent. There is a risk, however, that breaching confidentiality without informing the patient and in contradiction of patient refusal may seriously damage the trust between doctor and patient. In any situation where confidentiality is breached, doctors must be prepared to justify that decision before the General Medical Council.

Confidentiality and shared decision making

Although minors have rights of confidentiality, in most cases parents are involved in decision making. This report emphasises the ideal of a supportive, tripartite partnership between the young patient, parents and health professionals. The same ideal applies to treatments which are sensitive or controversial. For patients of any age, difficult decisions about serious or controversial treatments should ideally be made with factual medical information and moral support. Family support, however, is not always available and health professionals may face dilemmas about whether the family can even be informed.

As discussed in Chapter 2, those under 16 years of age are legally entitled to consent on their own behalf to any surgical, medical or dental procedure or treatment if, in the doctor's opinion, they are capable of understanding the nature and possible consequences of the procedure. The more serious the implications of the procedure proposed, the greater the degree of understanding required. While it is clearly desirable that children and young people have parental support for important and potentially life-changing decisions, young patients may exceptionally request that parents are not informed of a medical consultation or its outcome. This occurs with services such as contraception, abortion or requests for slimming pills. In such cases, health professionals should discuss the issues with the patient and point out the potential benefits of involving supportive adults. Dilemmas arise when mature and competent minors invoke their right of confidentiality. In such cases, the BMA advises that doctors encourage the young person to share information voluntarily. If they refuse, the BMA maintains that the duty of confidentiality owed to a patient under 16 is as great as the duty owed to any other patient and the refusal should be respected.

e)The medical duty to act only within one's sphere of competence

As with non-controversial areas of treatment, doctors should not exceed their own knowledge and competence. Clearly, innovative medical and surgical techniques are constantly being developed and it is important that specialists are able to provide those of proven benefit and adapt them, where necessary, for children and babies. Equally clearly, however, it is unethical for doctors, who may be on a steep learning curve, to fail to monitor their own mastery of the new technique and their own success rate in performing it in comparison with national rates or those of colleagues.

Doctors also risk exceeding their competence if they offer to provide, on another professional's recommendation, a category of care or treatment with which they themselves are unfamiliar. General practitioners, for example, are sometimes asked to prescribe and monitor new drugs which require specialist knowledge. They sometimes feel pressured to prescribe products unfamiliar to them which have a range of potential side-effects. Both the BMA and the General Medical Council emphasise the ethical duty of doctors to provide only those treatments which are within their own sphere of competence.

2. Examples of sensitive or controversial procedures

a) Procedures required for legal reasons

Some medical examinations, which lack a therapeutic purpose are carried out for purely legal reasons. Before seeking consent for the examination or test, its purpose should be clearly explained to the child, if sufficiently mature to understand, and to the parents.

Paternity testing

Paternity testing is usually carried out at the request of parents to clarify legal obligations for financial support but may have a lasting effect on the child's relationships with other family members. It is important that doctors try to ensure that those requesting paternity testing have thought about the potential effect the result may have on the child. The courts, however, have made it clear that determining the truth is usually best for the child. Thus, the health professionals role should be to consider whether the child's and family's needs for support and counselling are met rather than refusing to assist with the test. In the provision of counselling, the BMA advises that the child's interests as well as the adults' wishes should be taken into account.[4]

Assessment of age

Age assessment is also often carried out for purely legal reasons on young people applying for asylum or refugee status. If they are judged to be over the age of 18, their rights are significantly diminished. Expert medical opinion is that current methods of assessing age are not entirely reliable. Detailed guidance on this issue has been published by the Royal College of Paediatrics and Child Health.[5] The BMA strongly argues that in cases where their age cannot be verified, young people should be given the benefit of the doubt and given the rights accorded to minors.

Assessment in the case of alleged abuse

The primary consideration in the case of alleged child abuse or neglect must be the care of the child. In addition, the Crown Prosecution Service may also have an interest in clarifying whether sufficient evidence exists to mount a criminal prosecution against an alleged perpetrator. The conduct of medical examinations in the course of child protection proceedings is discussed further below.

b) Decisions requiring legal review

Some treatment decisions are so serious that the courts have said that each case should be brought before them for independent review. In the circumstances included in this section, it is essential that health professionals seek legal advice. Although, in general, the courts have often supported the views of health professionals in a range of sensitive or controversial cases, this is not invariably so. As Montgomery has commented:

> *a pattern has emerged of the courts listening to the health professionals' plans and, providing there is no serious disagreement between the professionals, authorising them to carry out their proposed care. This support for professional opinion is in no way automatic. It is not a legal rule. However, it is in practice highly likely that it will be the outcome of applications to court.*[6]

Sterilisation

Sterilisation is often requested for young women with serious learning difficulties. Because it fundamentally affects the scope of future choices, the courts have decided that the sterilisation of minors should only proceed with the authorisation of the court (unless sterilisation is a side-effect of an essential life-prolonging therapy, such as treatment for cancer). Patients should be encouraged and helped to participate in the decision to the greatest extent possible. Sterilisation of people under 18 has been the subject of a number of legal cases and is addressed in a practice note of the Official Solicitor.

Summary of Official Solicitor's guidance

The Official Solicitor's practice note states that "the sterilisation of a minor... will in virtually all cases require the prior sanction of a High Court Judge".[7] It is for the court to establish whether or not the sterilisation is in the minor's best interests. Courts require that it be demonstrated:

1. That the patient is, and is likely to remain, unable to make a decision on the matter;
2. That what it is being sought to avoid is likely to happen (in other words that the patient is likely to engage in sexual activity and is physically capable of procreation);
3. That if the condition it is sought to avoid arose, the patient would experience substantial trauma or psychological damage; and
4. There is no practicable, less intrusive alternative, and the matter needs immediate resolution.[8]

Before authorising the sterilisation of a young woman with learning difficulties, the court will wish to scrutinise the reasons for the request and will need to be convinced that other, less restrictive, options have been considered and appropriately rejected.

Sterilisation as part of menstrual management

Sterilisation may be recommended for menstrual disorders or for the menstrual management of young women with severe learning disability. In these cases, hysterectomy is often proposed. Clearly, this is a significant intervention and less drastic alternatives should be tried first. Oral or injectable contraception or a hormonally-loaded inter-uterine device may regularise and lighten menstrual bleeding. It must also be borne in mind that most women with learning disability can manage their own menstruation with appropriate education and support. In many cases, referral to special learning disability services rather than to gynaecological services is most appropriate.

Concern is sometimes expressed that the treatment is sought primarily for the benefit of carers rather than in the interests of the patient herself. Although attention is often drawn to the difficulty of separating out the "interests" of individuals in the family context, the court will need to be convinced that serialisation is the best option for the young woman.

Contraceptive sterilisation

Where a young person with learning disabilities is in a voluntary intimate relationship, contraception is likely to be required and, as with all other patients, the method should be that which best suits the individual. Some women with learning disability can be reliable pill takers although they require help from their carers.[9] Implants or other long-term contraceptive methods are appropriate for some patients. In all cases, surgical management should only be considered if less restrictive medical options are clearly inappropriate. Sterilisation for contraceptive purposes usually involves tubal ligation in young women. In such cases, health professionals must be able to demonstrate to the court that less invasive alternatives, such as oral or injectable contraception, are inappropriate.

The BMA remains particularly concerned by enquiries indicating that sterilisation is sought in order to preclude the possibility of pregnancy in residential care facilities where the family envisage that a patient may be exposed to sexual abuse. Medical procedures, such as the provision of contraception or sterilisation, should never be seen as a substitute or a safety net for inadequate supervision and support.

In *Re B*,[10] the House of Lords considered the proposed sterilisation of a 17 year old girl who was described as mentally handicapped and epileptic. Her mental age was judged to be five or six years. It was argued by the local authority which brought the application that she had no understanding of the connection between sexual intercourse and pregnancy, would not be able to cope with pregnancy or a child, and that she was exhibiting normal sexual drive and inclinations for a person of her age. B lived most of the time in a residential institution run by the council, and weekends and holidays at her mother's home. That she spent time away from the relatively secure environment of the residential home was part of the local authority's reasoning for the sterilisation. It was also part of the application that oral contraceptives were not an option for B, and that the only way to be certain to prevent pregnancy was sterilisation by occlusion of the Fallopian tubes. The application was granted, based on the court's assessment of B's best interests.

Re B (A minor) (Wardship: sterilisation)

In this case, the House of Lords held that:

> *A decision relating to the sterilisation of a child under 18 should only be made by a High Court judge, and a doctor who performs a sterilisation operation on such a child without leave of a court exercising the wardship jurisdiction will, notwithstanding that he has the consent of the child's parents, be liable in criminal, civil or professional proceedings.*[11]

BMA advice on sterilisation of young women

* Before any invasive options are considered, all feasible alternatives should be thoroughly explored. Treatment options recommended should be the least restrictive and always in the patient's best interests.

* The patient should be as closely involved as possible in the decision making process. Whenever possible, information should be obtained directly from the patient.

* Bearing in mind the patient's rights of confidentiality, advice should also be sought from those who look after patients whose competence is impaired. In addition to the family, professionals such as community nurses in the learning disability services, key workers and other professional carers should be consulted to ensure that an accurate picture of the patient's needs is obtained.

* Effort should be made to make the patient as much at ease as possible. A gynaecological examination is likely to be needed to assess or eliminate the possibility of organic disease. Health professionals should make every effort to ensure that the patient understands what the examination involves and consents to it.

Live donation of organs and non-regenerative tissue

Unlike bone marrow, the donation of non-regenerative tissue and whole organs by minors would require court approval and would only be considered as an option of last resort. The issue raises a number of problems, including the ethical difficulties involved in separating the interests of the child from those of the family as a whole. Only very rarely can the interests of children and young people be seen isolation from the context of their close relationships. Most people accept that there are special rights and responsibilities inherent in the family relationship but the duties are primarily those duties owed by adults to their children. Parents may have a difficult choice concerning how the various interests of each child can be protected where one child needs a life-saving transplant and another is a potential donor.

Competent minors.

In the case of competent minors, their own consent should be sought. As with all medical interventions, information must be given to them in terms they can understand. Lord Donaldson, in a case on another issue in 1992 commented that if a young person is *Gillick* competent, both the parents and the potential donor would have to give consent to donation. He added that doctors would be well advised to seek guidance from the courts as well.

The most common argument put forward in support of donation by a minor is that it is the last option and that the donor benefits emotionally if the life of a sibling is saved. The donor child may, however, have mixed feelings about a sick brother or sister who is the focus of the family's attention. Children must be given appropriate opportunities to express without feeling guilty their own needs, as well as their fears, ambivalences or anxieties. Therefore, notwithstanding the importance of shared decision making within families, health professionals should also have an opportunity to talk privately with the young person to explore any anxieties and any intentional or unintended pressures.

Babies and young children.

In some cases, the child is not competent to give independent consent. Parents sometimes generate a new pregnancy, for example, so that the future child will have compatible tissue with a sick child in the family and be able to donate. The issue of live donation of organs or non-regenerative tissue by a person unable to give consent has not been considered by the courts in the UK [check this]. The court has, however, considered the donation of bone marrow by a mentally incompetent adult woman to her sister.[12] That application was successful, based in large part on the benefits which would accrue to the mentally incompetent woman. Connell J said that she would receive "an emotional, psychological and social benefit from the operation and suffer minimal discomfort". He warned, however, that:

> *It is doubtful that this case would act as a useful precedent in cases where the surgery involved is more intrusive than in this case, where the evidence shows that the bone marrow harvested is speedily regenerated and that a healthy individual can donate as much as two pints with no long-term consequences at all.*[13]

It is unclear, therefore, how the courts would deal with a case involving, for example, the live donation of a kidney from a child. The BMA, however, has serious reservations about children donating whole organs or non-regenerative tissue. In any such case legal advice must be sought and an application to the court will be necessary.

BMA advice on organ or non-regenerative tissue donation by minors

* The BMA has serious reservations about the use of children and young people as live donors of organs and non-regenerative tissue;

* Donation should not be considered when the risks are not clearly in balance with the expected benefits for that child and the family as a whole. The BMA recognises that the benefits for the donor may be psychological or retrospective, arising from the knowledge that the minor has saved the life of a sibling.

* Donation should only be allowed where it is not judged to be clearly prejudicial to the long-term health of the potential child donor. The BMA recognises that the long-term risks to donors sometimes cannot be adequately predicted but a cautious evaluation should be made based on the current state of medical knowledge.

Refusal of blood products

Refusal of blood products is discussed in Chapter 2 (on the legal position) and in Chapter 5 (on refusal of potentially life-prolonging treatment) and so it is merely flagged up here as a sensitive issue about which health professionals continue to express some uncertainty. As mentioned in Chapter 2, the courts have been willing to override a refusal of blood by a competent young person. The legal system has also considered a small number of cases where the parents of a child requiring a blood transfusion have refused to give their consent to treatment on religious grounds[14]. Lawyers[15] in various jurisdictions, however, have drawn attention to the risk that health professionals may too rapidly assume that recourse to the courts to overrule a refusal - either by the child or by parents - is inevitably the only way forward. If this were the case, it may mean that time is not given, even in non-urgent situations to the exploration of potential alternatives to the use of blood.

Clearly in such situations, attempts should be made to negotiate with the family in an attempt to find an acceptable solution. Invariably, the family is anxious to save the child's life if this can be done in a way which does not contravene their beliefs. Sometimes, this may be possible by a referral to a specialist centre where techniques, such as bloodless surgery are practised. Lists of current centres of excellence in such techniques and of physicians willing to work constructively with Jehovah's Witness families are held by the Jehovah's Witness Hospital Liasion Committee. [16]

Where negotiation fails to resolve the disagreement, however, it is likely that the law will be involved. Courts have indicated that the administration of blood transfusions to Jehovah's Witness children against the wishes of their parents should not be carried out without the approval of a court. Although these cases make no reference to the appropriate procedure in an emergency situation, Lord Templeton made the general point, in *Gillick v West Norfolk and Wisbech Health Authority* that:

> *"Where doctor and parent disagree, the court can decide and is not slow to act. I accept that if there is no time to obtain a decision from the court, a doctor may safely carry out treatment in an emergency If the doctor believes the treatment to be vital to the survival or health of the infant and notwithdstanding the opposition of a parent or the impossibility of alerting the parent before the treatment is carried out.*[17]

Persistent vegetative state (PVS)

Despite the voluminous medical literature and ethical and legal commentaries on persistent vegetative state[18], until recently very little guidance has specifically addressed the situation in relation to children. Nevertheless, there has been considerable debate about general aspects of the condition in adults, including discussion about the value of rehabilitative efforts in the early phase before a diagnosis is finalised. The degree of disagreement that has arisen may be at least partly indicated by the fact that even the terminology is a matter of dispute, with some organisations such as the BMA continuing to refer to "persistent" vegetative state, the Royal Colleges referring to "permanent" vegetative state and some legal commentators calling it simply "the vegetative state".

In 1996, guidance from the Royal College of Physicians noted that "it is a diagnosis which is not absolute but based on probabilities". It stated that "the diagnosis can be made at birth only in infants with anencephaly or hydranencephaly. For children with other severe malformatins or acquired brain damage observation for at least six months is recommneded until lack of awareness can be established."[19] In 1997, the Royal College of Paediatrics and Child Health issued guidance, clarifying a number of situations in which withdrawal or withholding of medical treatment might be considered and included permanent vegetative state among these. The guidelines defined PVS as:

"a state of unawareness of self and environment in which the patient breathes spontaneously, has a stable circulation and shows cycles of eye closure and eye opening which simulates sleep and waking, for a period of 12 months following a head injury or 6 months following other causes of brain damage."[20]

Guidance from the College concludes that "treatment, inclusive of tube feeding may be withdrawn whilst making the patient comfortable by nursing care." The BMA has also published guidance on the withdrawal and withholding of life-prolonging medical treatment, including artificial nutrition and hydration, covering both adults and children.[21] This recommends that legal advice be sought before life-prolonging treatment is withdrawn. The precedent for this advice was set in 1993 by the House of Lords' decision in the case of an adult PVS patient.[22] As yet, there have been no reported cases of applications to withdraw artificial nutrition and hydration from a PVS patient under the age of 18. In the first major English case on this subject, the patient was Tony Bland, a 21 year old victim of the Hillsborough football stadium disaster. It was acknowledged at the time that Bland's condition was very extreme, and that withdrawing artificial nutrition and hydration was a very emotive step. The Lords therefore recommended that for the time being, all cases where the withdrawal of artificial nutrition and hydration was being considered from a patient in PVS should be subject to court review. This was clearly intended as an interim measure, but until a clear statement is made to the contrary, a declaration should always be sought for PVS patients. The Official Solicitor has published a practice note on the vegetative state.

Summary of the Official Solicitor's PVS Practice Note

- Applications to court should follow the procedure laid down for sterilisation cases;
- Applications in respect of minors should be made within wardship proceedings;
- The applicant should seek 'leave' for termination of feeding and hydration (rather than a 'declaration');
- Cases are normally held in open court but steps can be taken to protect confidentiality;
- Views of the next of kin "must be taken fully into account by the court";
- Any relevant views previously expressed by the patient should be taken into account.

c) Other sensitive or controversial procedures

Whilst there are few procedures in which the courts are required to be involved, there are other controversial questions where it would, nevertheless, be prudent to consider whether a legal opinion should be sought. Where there is doubt about the validity of the consent provided, or the legitimate scope of parental consent, advice should be sought.

Research

Research which poses more than minimal risk to the child is unacceptable although the difficulties in arriving at a widely agreed definition of this concept have already been mentioned. Dilemmas arise, however, from the fact that better treatment options for children's diseases cannot be developed without involving children in research projects. The dilemma is less acute where there is some reasonable prospect of the child benefitting personally, but in some cases there will be no direct benefit to the child. The moral basis of research is that information gained from one patient's experience should, where feasible, be used to help others as effectively as possible. Obviously, research should not, however, disadvantage or inconvenience the research subjects without their knowledge and informed consent. Much research on babies and young children involves relatively minor interventions such as the taking of blood samples. Where these are additional to the blood tests required for the child's own medical treatment, it is important that parents are fully aware that the samples are for research purposes and that they can refuse such use without any detriment to the child's treatment. Also it is vital that all research projects are carefully scrutinised by an appropraitely constituted research ethics committee which considers the potential impact of the research on the research subjects.

Children should not be subject to procedures which do not benefit them and which cause pain. Differences of opinion have been expressed about how this should be defined, with some commentators seeing venepuncture as a painful procedure, when viewed from the child's perspective. The former British Paediatric Association, (now the Royal College of Paediatrics and Child Health), for example, pointed out that the prospect of blood sampling or injections particularly upsets some children[23] and that a child's refusal on that score should be considered as seriously as an adult's refusal to participate in research because of an extreme dislike of venepuncture. The BMA notes that there is a divergence of views on this point and believes that cases have to be considered on an individual basis. As with all research, the objective must warrant the intervention and children should have the opportunities to discuss their own perspective on what is proposed. The BMA supports the BPA advice that research workers "must recognise when a child is very upset by a procedure and accept this as genuine dissent from being involved." Clearly, individual consent for participation in research should be sought from competent minors. Parents should also be involved in decisions about research.

Records-based research

Some records-based research is carried out in parallel with the provision of treatment by health professionals who already have access to the records as part of their duty of care. In such cases, where the researcher is in effect working on the data from his or her own patients, there is no breach of confidentiality as only those who already have access to the information, use it for research. Clearly, the permission of patients would be a pre-requisite if any conclusions were published which, even indirectly, identified them.

Much records-based research involves no contact with the patient, whose data should be anonymised to prevent identification. No disadvantage is caused to the individual whose anonymised information is used. Nevertheless, families need to be generally aware if their data are likely to be used in this way and have the choice of opting out. As with all research, express authorisation for the detailed research protocol should be obtained from an appropriately constituted research ethics committee. The fact that a research project is solely records-based does not necessarily mean that it is exempt from the requirement for review.

Research involving patients, including randomised controlled trials

Traditionally, research has been divided into two broad categories: "therapeutic" research in which the pursuit of knowledge is combined with trying to improve a patient's care and "non-therapeutic" which simply aims to extend knowledge but not benefit individual patients. It is accepted that all patients may ethically be involved in the former, with their consent (or with parental consent on behalf of young children). Competent adults can also choose to participate altruistically in research to benefit others. Competent and mature children could also probably give ethically valid consent to such participation if it could be demonstrated that there was no pressure whatsoever put upon them to agree. Nevertheless, a basic principle of research is that projects which could equally well be done on adults should never be done on minors. While adult volunteers should be the first to test out new procedures or to compare competing treatment options, their participation is not always useful for assessing how children would fare in similar circumstances. Thus, well regulated research invlving children is essential to the improvement of services for them and the development of new treatments to extend or improve the quality of their lives.

Clearly, there has been considerable debate over the last fifty years regarding the involvement of non-autonomous people, including young children in research that offers them no direct benefit. In the early 1960s, for example, the Medical Research Council first drew attention to what broadly remains the strict legal position.

MRC 1962 Statement on Paediatric Research

"*It should be clearly understood that the possibility or probability that a particular investigation will be of benefit to humnaity or to posterity would afford no defence in the event of legal proceedings. The individual has rights that the law protects and nobody can infringe those rights for the public good. In (non-therapeutic) investigations it is, therfore, always necessary toensure that the true consent of the subject is explicitly obtained..**In the strict view of the law, parents and guardians of minors cannot give consent on their behalf to any procedures which are of no particular benefit to them** and which may carry some risk of harm*".[24]

It was later legally clarified, however, that a person with parental responsibility can consent to an intervention which although not in the best interests of that child is not *against* the child's interests, for example a blood test.[25] It is now widely accepted that from an ethical perspective research can be carried out on children, when there is no expected benefit for them individually, provided there is minimal risk, strict safeguards and there is no objection from either the child or parents. Thus in 1991, the MRC re-visited its earlier statement on non-therapeutic paediatric research and extended its guidance to reflect a broad consensus that children can participate in research, subject to strict safeguards.[26]

Summary of 1991 MRC Statement on Paediatric Research

- Research should only involve children where this essential and where the information cannnot be obtained using adult volunteers;
- All projects must have LREC authorisation;
- Mature children must be willing to participate before they can be included;

Therapeutic research

- Minors who have sufficient understanding can consent. If over 16, parental consent is not essential but is advisable if the child's level of understanding is in doubt. If under 16, their own consent should be complemented by the consent of parents or guardian;
- Children who lack sufficient understanding can be included if parents or guardians consent and consider that the benefits outweigh the harms for that child;

Non-therapeutic research

- Competent minors can consent but it would also be prudent to have parental or guardian's consent;
- Minors who cannot consent can be included in such research, subject to safeguards and where they are not placed at more than neglible risk of harm;
- In that case, parents or guardians must consent and agree that there is no more than neglible risk;
- The LREC should consider the likely risk which should be no more than the discomfort encountered in daily life or during routine examinations.

The boundary between treatment and research

Unusual treatments frequently involve some element of research even though this is not the main goal of modifying a standard procedure. Consent to treatment, however, must be kept separate from the consent to the treatment being monitored for research purposes. Where the monitoring simply involves the recording of information that would be collected in any case during the course of treatment, this clearly has fewer implications. Nevertheless, the family should be kept aware that information gained from the treatment may, in an anonymised form, help inform others in the same situation.

As a general principle, all doctors must be assiduous in monitoring outcomes from their treatment patterns and investigate the reasons if their success rates fall below those achieved by other practitioners in similar circumstances. They should also participate in audit initiatives. Clinicians have always modified standard treatments in individual cases where they have reason to believe that a particular patient is likely to thrive better under a different regime. It is essential, however, that the outcome from such modifications is also carefully monitored and recorded. If success rates appear consistently better with a modified procedure, a formal research protocol should be drawn up for appraisal by a research ethics committee and the innovative treatment put to the test.

Additional BMA Recommendations for research involving children

* Research involves partnership with the child and/or a family who should be kept informed and consent to each separate stage of the project;

* Researchers must take account of the cumulative medical, emotional, social and psychological consequences of the child being involved. Children with some conditions may be exposed to a sequence of research projects. It is insufficient to consider only the risks of a particular research procedure without considering the background context and whether the child has been involved in multiple projects by different researchers;

* Researchers should be aware of the possibility of the procedures giving rise to emotional or behavioural disturbances in the child and deal with any such disturbance by prompt and appropriate referral;

* Research workers must recognise when a child is very upset by a procedure and accept this as a valid refusal.

* Researchers should be aware (and attempt to avoid) any pressures which might lead the child to volunteer for research or which might lead parents to volunteer their children, in the expectation of direct benefit.

Innovative treatment

As a general principle, children and young people should not be put forward for innovative treatment which involves an unknown risk and which has not previously been tested on informed adults. When considering newly evolving procedures in xenotransplantation, for example, the BMA stipulated that the first recipients of genetically modified animal organs must be adult volunteers. Generally, children should only be offered new forms of treatment once the safety and benefit has been proven in treatment of adults. Exceptions, however, may occur in situations where there is evidence to suppose that the child's chances of recovery with treatment are better than those of an adult with a comparable condition.

By their nature, innovative treatments have less evidential support than conventional regimes. The benefit for the patient is harder to predict. At the same time, there is likely to be an intuitive wish to try anything that might help save or improve a child's life. Clinicians may be more tempted to take an over-optimistically positive bias in recommending treatment than they would do for an older person who has already lived a full life. Parents and the patient often find it very hard to resist agreeing to any therapy - even unproven treatment - which doctors recommend.

The value of a second opinion

It is, therefore, essential that clinicians make clear which aspects of treatment are innovative so that the family can assess the proposal in the light of that knowledge. If the treatment involves significant risk to the child, an independent and objective second opinion should always be sought before presenting the option to the family. This means that the clinician can be more confident that he or she is not putting too positive a gloss on it when explaining the option to the family. When the new treatment is invasive, the procedure for obtaining informed consent must reflect the gravity of that. Families should be fully informed if a particular practitioner or hospital introduces, on a routine basis, procedures which are not standard treatment in other facilities. It is no longer ethically acceptable for a department to rely on the concept of implied consent on the grounds that an innovative treatment is "standard" when this is plainly not a widely shared view. Families should be aware of all the options open to them even if this involves referral to another facility. Consent can never be implied or taken for granted in this situation. For all research projects and treatments which span the border between research and innovative treatment, approval should be sought from an appropriately constituted ethics committee.

Innovative therapy and Child B

B who was 10 years old suffered from non-Hodgkin lymphoma with common acute lymphoblastic leukaemia. In 1993, she developed acute myeloid leukaemia and after a variety of treatments, including chemotherapy and a bone-marrow transplant, B was only given six to eight weeks to live. B's doctors maintained that B should be given palliative care to enable her to enjoy a normal life during her remaining weeks. American specialists consulted by B's father, however, estimated that a further two stages of treatment were possible, both of which had a 10-20% chance of success: the second stage being contingent on the first succeeding. B's father asked the Health Authority to allocate the £75,000 necessary to purchase this treatment. The Authority refused on three grounds: (I) the clinical opinion of B's usual health care team was that the treatment was not in her best interests; (ii) the treatment was non-proven, experimental and had never been formally evaluated; (iii) the treatment was not an equitable or effective use of resources given the small prospect of success. Although when the case went to court and to appeal court, much of the discussion concerned the expenditure involved, the fact that the treatment was, as Sir Thomas Bingham termed it "on the frontier of medical science" without "a well-tried track record of success" also played a part. Evidence in the Appeal Court focussed also on the view of the specialist who had cared for B since the child was 5 that "it would not be right to subject B to all this suffering and trauma when the prospects for success were so slight".[27]

Medicines for children

Although not generally perceived as innovative treatment, a common area of concern for doctors is that pharmaceutical products are licensed only for adults although children may need them. The drugs cannot be licensed for children if insufficient research data exist about the effect on children. Although they can be prescribed for young patients, the product license and patient information relates only to the known effect on adults. The optimum dosage for a child may be a matter of trial and error although considerable work is being done to produce guidance in this area of treatment for children. A formulary of medicines for children is published by the Royal College of Paediatrics and Child Health.[28] The College, together with the Neonatal and Paediatric Pharmacists Group also provides guidance on the use of licensed medicines for unlicensed applications or unlicensed medicines in paediatric practice. In general, in their view, "it is not necessary to obtain the explicit consent of parents, carers or child patients to prescribe or administer licensed medicines for unlicensed applications or unlicensed medicines." Both organisations emphasise, however, the importance of health professionals ensuring they have sound information about any medicine they prescribe, dispense or administer.

Examination Or Assessment for Child Protection Purposes

The need for consent

Except in an emergency, any examination or assessment which involves physical contact with the child will require consent (from a parent, some other person with parental responsibility, or a competent child), or authorisation from a court.

Some assessments do not involve physical contact (for example an interview as part of a psychological or psychiatric assessment). The courts, however, have stated that a decision whether a child should be interviewed is an aspect of parental responsibility[29]. Therefore, unless the child is mature enough to agree to the assessment, it is necessary to seek agreement from a person with parental responsibility, or authorisation from a court. As in other contexts, any person with parental responsibility may provide consent. The opposition of one person with parental responsibility does not prevent a valid consent being given by another person with parental responsibility. Therefore, for example, if there are concerns about the possibility of abuse by a child's father, it may be possible to obtain consent for an assessment from the child's mother. If an assessment is necessary, and no valid consent can be obtained it is necessary to apply to a court for authorisation of an assessment.

Requirements for valid consent to a child protection assessment

To obtain a legally valid consent, it is necessary for the person giving consent to be informed of the nature and purpose of the proposed assessment. Therefore where the purpose of the assessment is to establish whether or not a child has been abused, the person giving consent should not be deceived about the purpose. Being open about the purpose is clearly necessary when an assessment is requested by a statutory agency responsible for child protection (for example, social services, the NSPCC, or the police).

At the earliest stages of a case, before other professional agencies are involved, child abuse may be one of several possible explanations for a child's condition. Where an assessment is to evaluate the child's health needs, it would be counter-productive to mention prematurely the possibility of child abuse. Therefore, the amount of information which must be disclosed when seeking consent is a matter for careful professional judgment, taking account of the level of professional concern at the time. Guidance[30] on this has been issued by the Department of Health, the BMA and the Conference of Medical Royal Colleges which provides a description of the development of professional concern:

BMA/Health Department/Royal colleges' guidance

"Child abuse may present in a variety of complex and intricate ways; for example as a suspicion when signs and symptoms are present but their significance is unclear, with clear physical signs or with an allegation or a disclosure. Where there is clear evidence of abuse or if an allegation has been made there should be no delay in referring this to the statutory agencies.

Where uncertainty exists doctors will often find it helpful to test out professional hypotheses before initial concerns about child abuse are shared with non-medical colleagues. Doctors should clarify their own thoughts about a particular case, and with advice as appropriate from senior or more experienced colleagues, reach a critical threshold of professional concern. When a critical threshold of professional concern is reached doctors must be prepared to share these concerns with the statutory agencies for further evaluation and discussion within a time frame which is not detrimental to the child's interests.

The critical threshold of professional concern is a matter of individual professional judgement made by someone with experience in child protection matters and will inevitably vary between professionals and between situations. Training, supervision and experience will be crucial, however, in determining where this threshold is set."

Once a critical threshold of professional concern has been reached, it becomes necessary to share information and concerns with other agencies before further assessments take place.

Detailed guidance on the role of different agencies, including medical professionals, within the child protection systems is contained in various Department of health publications.[31]

The need to avoid unnecessary assessments

The courts have emphasised that it is harmful for children to be exposed to an unnecessarily large number of assessments. For example, in *Re CS*[32], a child was subjected to 12 intimate physical examinations by the same doctor. Mrs Justice Bracewell said

> *"By reason of the failure of the court to control the examination of [the child], she was, in my judgment, subjected to abusive intimate examinations on more occasions than could possibly be justified."*

Once legal proceedings have begun, the court is responsible for deciding whether an assessment is required for the purposes of the proceedings, having regard to the child's welfare. Nevertheless, there is a danger that children may be repeatedly assessed *before* court proceedings have been initiated. For example, one parent may be convinced that the other parent is abusive, and be determined to seek evidence to confirm this. In other cases, a parent may agree to a series of assessments at the request of a local authority, because of a fear that the local authority will initiate care proceedings if consent is not granted. In such situations, professionals must exercise independent judgment to decide whether a further assessment is necessary and in the child's interests.

Where there are concerns that inappropriate and unnecessary assessments are being carried out, it has been suggested that an order can be sought from the court, prohibiting a parent from granting consent to further assessments[33].

The role of the court under the Children Act 1989

Once legal proceedings under the Children Act 1989 have been initiated, the court is responsible for making decisions about the conduct of the proceedings, including whether any assessments should be carried out. The Family Proceedings Rules 1991 state:

"No person may, without the leave of the court, cause the child to be medically or psychiatrically examined, or otherwise assessed, for the purpose of the preparation of expert evidence for use in the proceedings."

Therefore, before undertaking an assessment for the purpose of legal proceedings, medical professionals should confirm that the court has granted permission (known as 'leave') for the assessment. Obviously this requirement does not prevent any assessment which is necessary for the child's health, since this is not undertaken for the purpose of the preparation of expert evidence. In addition, when the court makes certain orders under the Children Act 1989, it can positively direct that an assessment should take place, or direct that there is be no examination of the child. For example section 38 of the Act states:

"(6) Where the court makes an interim care order, or interim supervision order, it may give such directions (if any) as it considers appropriate with regard to the medical or psychiatric examinations or other assessment of the child; but if the child is of sufficient understanding to make an informed decision he may refuse to submit to the examination or other assessment.

(7) A direction under subsection (6) may be to the effect that there is to be -
(a) no such examination or assessment; or
(b) no such examination or assessment unless the court directs otherwise."

Similar provisions apply to emergency protection orders (section 44) and child assessment orders (section 43).

Refusal of examination

It is significant that these sections of the Children Act which allow the court to direct that an assessment should take place, also state that a child who is of sufficient understanding to make an informed decision may refuse to submit to the examination or assessment. Therefore, even where an assessment has been specifically authorised by a court, it is still necessary to assess the level of the child's understanding, and to seek the child's agreement, before proceeding with the assessment. (See Chapter 4).

Recommendations concerning a child's refusal

Where a child refuses to cooperate with an assessment, there are several possibilities:

- It may be decided that assessment is impossible without the child's cooperation, or that it would be inappropriate to proceed in the face of the child's objections. In these circumstances, further directions should be sought from the court.

- It may be decided that the child lacks 'sufficient understanding to make an informed decision'. In these circumstances, the assessment can proceed, despite the child's objections. Health professionals, however, may well be unwilling to proceed in such circumstances. If it is likely to be necessary to use force or sedatives to overcome the child's resistance, it would be advisable to seek the specific authorisation of the court for these measures.

- It may be decided that the child has 'sufficient understanding to make an informed decision'. In these circumstances, the court has no power under the Children Act to override the child's refusal. However, in the case of *South Glamorgan County Council v W and B*[34], it was decided that the High Court exercising its 'inherent jurisdiction' may authorise an assessment against the wishes of a competent child if the child would otherwise be likely to suffer 'significant harm'. This power is not available in magistrates' courts or county courts.

Carrying out assessments of children against their wishes are very controversial. Such assessments are unlikely to be appropriate unless:

- there is a high probability that useful evidence can be obtained; and
- the evidence cannot be obtained in any other way; and
- the benefit to the child from obtaining the evidence outweighs the burdens involved in imposing the assessment on the child.

The role of the expert witness

Specific guidance on providing expert evidence for courts is provided in the professional literature. There are now also a large number of judicial decisions, where the courts have given guidance on the appointment of experts. The important points can be summarised, as below.[35]

Information to be provided to Experts

- Experts should seek further information and documentation when required.
- Doctors who have prior clinical experience of a child should have all clinical materials in advance of the hearing for inspection by the court and other experts eg medical notes, hospital records, x-rays, photographs and correspondence.
- Experts who are to give evidence must be kept up to date with developments in the case relevant to their opinions and it is the duty of the solicitor instructing the expert to provide such information.

Duties of Experts

- Expert evidence presented to the court should be, and should be seen to be, the independent product of the expert, uninfluenced by others. Experts should provide independent assistance to the court by objective unbiased opinion, in relation to matters within their expertise.
- Experts should state the facts or assumptions on which their opinions are based, and should not omit to consider material facts which detract from their conclusions.
- Experts should make it clear when a particular aspect is outside their expertise.
- If an expert opinion is not properly researched by reason of insufficient data, then this must be stated with an indication that the opinion is provisional.
- If at any time an expert changes his or her opinion on a material matter, this information must be communicated to the other parties, and when appropriate, to the court.
- If an opinion is based, wholly or in part, on research conducted by others, this must be clearly set out in the report, the research relied on must be identified,

and the expert must be prepared to justify the opinions expressed.

Male Infant Circumcision

Some measures, such as male, infant circumcision, are not primarily done for any therapeutic reasons but in pursuit of cultural or religious goals of parents.[36] The ethics of submitting a child to an irreversible, invasive procedure to fulfill the wishes of other people raises difficult questions. Such concerns have to be weighed, however, against the claim that various social or psychological benefits may be conferred by such a procedure which symbolically brings the child into a particular community.

There is an increasing divergence of medical opinion about the harms and benefits of male infant circumcision for religious or cultural reasons. The BMA does not accept that there is sufficient evidence of a clear health benefit for this alone to justify circumcision. The Association has published a guidance note on the various arguments and reviewing the existing medical evidence[37]. This emphasises that doctors should not circumcise babies or young boys unless convinced that this in the individual child's best interests. This requires consideration of a range of medical, psychological, social and cultural factors. Where doctors are convinced it would be in the child's interests, written consent must be obtained from all those with parental responsibility. This usually means consent is needed from both parents, who should be first informed of the implications and risks of the procedure.

The case of J

J was five years old. His parents were separated, and he lived with his mother, a non-practising Christian. His father sought two specific issue orders, one that J be brought up in the Muslim religion, and the other that he be circumcised. With regard to the first, J was found to be of mixed heritage, and to be living an essentially secular lifestyle. His father observed only some aspects of Islam, and J's only contact with that faith was through his father. It was therefore considered impractical to require J to be brought up in this religion. His mother opposed the circumcision. The court's judgement was finely balanced on the facts of the case but it concluded that it would not be in J's best interests to be circumcised. A prohibited steps order was issued to prevent the father from arranging J to be circumcised. The judge went on to say that "where there is a dispute between parents or other persons having parental responsibility for a child over the child's circumcision, that dispute should be referred to the court for resolution".

Re J (A minor) (Prohibited steps order: circumcision)

Contraception

Sexual activity among young people has increased consistently since the 1960s. In most cases, the decision to embark on an intimate relationship is voluntary but in some instances the risk of abuse or exploitation requires sensitive investigation. In some cases, peer pressure is likely to be a factor in early sexual activity. The possibility of this exercising a disproportionate influence on the young person's decision can be raised, where appropriate, by health professionals advising young people.

Advisory role of health professionals

In the BMA's view, when young people decide to have a sexual relationship, health professionals should be able to give them frank advice, particularly information about how to minimise risks to their future health. If the patient appears too immature or lacking in understanding to provide a valid consent to the provision of contraceptive services, that should also be discussed and the health professional should explain the reason for declining to provide that service. Early unprotected sexual intercourse may increase a number of health risks, including that of HIV infection and other sexually transmitted disease. For young women, the risks include carcinoma of the cervix as well as the physical and psychological effects of pregnancy. Information about avoidance of pregnancy and sexually transmitted disease should be available for both sexes and can be supplemented by encouraging in young people a sense of responsibility with regard for their own present and future health.

Primary care health professionals, in particular, have a vital role in this matter but some young people are apprehensive about talking to their GP for fear that confidentiality will not be respected. They worry that their GP will discuss with their parents any requests for contraceptive services. A primary task, therefore, must be to educate young people about the confidentiality they can expect from their doctor.[38] (See also Chapter 3).

Doctors consulted for contraception must:

(I) consider whether the patient understands the potential risks and benefits of the treatment and the advice given;

(ii) discuss with the patient the value of parental support. Doctors must encourage young people to inform parents of the consultation and explore the reasons if the patient is unwilling to do so. It is important for persons under 16 seeking contraceptive advice to be aware that although the doctor is legally obliged to discuss the value of parental support, the doctor will respect their confidentiality.

(iii) take into account whether the patient is likely to have sexual intercourse without contraception;

(iv) assess whether the patient's physical or mental health or both are likely to suffer if the patient does not receive contraceptive advice or treatment; and

(v) consider whether the patient's best interests would require the provision of contraceptive advice or treatment or both without parental consent.

Abortion

Britain has the highest teenage pregnancy rate in Europe. Pregnancy in under-16s is usually not a planned event and the majority of young women who become pregnant before the age 14 or 15 have an abortion. Doctors are, therefore, faced by increasing numbers of requests for a termination by young patients who are capable of consenting to that procedure and whose cases fall within the legal scope of the Abortion Act. Some of these insist that parents must not be informed. In some cases, patients fear that their parents will disown them if they find out. Awareness of the potential emotional and psychological sequelae of abortion, however, makes doctors anxious about the lack of family support mechanisms for such patients. Counselling may help the patient to identify supportive adults within or outside the immediate family. Ultimately, however, a patient's request for confidentiality should not be overridden except in very exceptional cases. Examples of such cases arise where the patient is already a ward of court[39] or where there is evidence to indicate that the patient is being exploited or is the victim of sexual abuse.

If a competent young patient agrees to parents being involved, their consent should also be sought to the termination. In some cases, however, parents attempt to override the consent provided by the patient herself. This was the situation in the cases of P and L.

The case of P and the limits of parents' power to refuse abortion[40]

P was 15 and in local authority care after a conviction for theft when she gave birth to a baby boy. Soon after the baby's birth, she became pregnant again and, as with her first pregnancy, her parents refused to consent to an abortion. Part of their objection was on religious grounds since P's father was a Seventh Day Adventist. P herself wanted to terminate her second pregnancy. The local authority made P a ward of court and asked the court to authorise a termination. P's father opposed this, suggesting that P should give birth and take care of the second child while he and his wife raised the first. Justice Butler Sloss, however, concluded that the second pregnancy endangered P's mental health, impeded her schooling and endangered the future of P's existing child. She had no doubt that continuance of the pregnancy involved greater risk for P and her existing child than the risks of the termination. P's welfare, as a ward of court had to be the judge's paramount consideration and the court also had to consider the welfare of P's existing son. The judge concluded that the parents' objections did not outweigh the risks to P's mental health if the pregnancy continued. Their wishes could not "weigh in the balance against the needs of this girl so as to prevent the termination" which was ruled to be in P's best interests.

The case of L[41]

L was a pregnant 12-year old who wished to have an abortion. L had been raised by her grandparents who supported her wish but L's mother, who had maintained close contact with L, did not agree and opposed an application by the local authority for L to have a termination of pregnancy. Notwithstanding the mother's objection, the judge concluded that an abortion would be in L's best interests, given her age and small build, the trauma of an unwanted pregnancy and the disruption to her education.

If a young pregnant person is assessed as lacking "Gillick competence", a person with parental responsibility can legally consent to her undergoing a termination. In all cases, the patient's views must be heard and considered. If an incompetent minor refuses to permit parental involvement, expert legal advice should be sought. This should clarify whether the parents should be informed against her wishes. The termination cannot proceed without valid consent, except in an emergency. This may require an application to the courts. If doctors believe that the patient is insufficiently mature to consent validly to termination of pregnancy, this raises the question of whether the patient was also unable to consent to sexual intercourse. Rape is invariably a serious crime which must be investigated. The first duty of health professionals concerns the welfare of the patient who may need to be referred for specialised help.

Treatment for Sexually Transmitted Disease

Sexually transmitted disease is a risk for both young men and young women. While STDs generally, and HIV specifically, present risks to all sexually active age-groups, these risks may be particularly acute for young people, some of whom may have a higher than average rate of partner change. Young people are also likely to feel less confident about insisting on safe sex practices. Evidence suggests that adolescent girls have a higher prevalence of cervical ectopy than adult women which makes them especially vulnerable to infections such as chlamydia. This can permanently damage fertility. Young people of both sexes can benefit from confidential advice on prevention of HIV and other STDs, which can be given during consultations related to contraception or other appropriate occasions.

Some dilemmas raised by doctors, with the BMA, with the BMA focus on the issue of confidentiality in cases where the patient may be risking his or her own health and that of other people. For example, young patients sometimes give false details and contact addresses and although testing positive for STDs, fail to turn up for the test result. Attempts at follow-up are likely to entail some potential breach of confidentiality. It is important, wherever possible, that these issues are broached with the young person at the time of the initial consultation or test.

When a young person is in the care of a local authority, there may also be arguments in favour of informing the authority, especially if the patient is in a care facility where others are likely to be at risk of infection. Although confidentiality can usually be safeguarded, absolute confidentiality cannot be guaranteed for any patient and in exceptional cases, information may have to be disclosed.

Genetic testing

The BMA notes that there is broad support for the availability of genetic testing of children in certain situations:

- Diagnostic testing of symptomatic children to identify the cause of their illness;
- Testing of children at risk of a disease that would regularly present in early childhood; and
- Presymptomatic predictive testing to identify children who may benefit from early treatment.

Despite the fairly wide consensus on testing in these circumstances, there are other forms of genetic testing which are more controversial. Of these, debate so far has concentrated on two main areas:

- Carrier testing that will only be of interest to the child when he or she is planning a family; and
- Predictive genetic testing for late onset diseases where no treatment is available.

The BMA has considered these issues in some depth in its publication *Human Genetics: Choice and Responsibility*. A summary of the BMA's views on these issues is set out below.

Carrier Testing

Carrier testing of very young children, who are clearly not competent to give consent, raises difficult issues. Because the information has no practical relevance while the child is young and will not be utilised until some time after the child is sufficiently mature to take control of his or her own health care, there are strong arguments for delaying testing until the child is sufficiently mature to make a personal decision. Many parents, however, wish to know whether their child is a carrier of the disorder for which the family is at risk. In reality, the interests of the child cannot be considered totally in isolation from the interests of its parents and other family members. Although it may appear to be contrary to the child's interests to test the child in order to relieve the concerns of the parents, health professionals recognise that family dynamics and cohesion are important to all of the individual family members and their wellbeing. Disharmony in one sphere may lead to a breakdown, or difficulties, in relationships within the family, which, in some circumstances, may be of more harm to the child than acceding to the parent's request.

With requests for carrier testing, the young child's rights to make his or her own decisions in the future, to confidentiality and to be protected from potentially harmful information appears to conflict with the parents' "right" to choose testing for their child and to make decisions which they perceive to be in their child's best interests. The BMA believes that there should be a presumption against testing young children for carrier status, whilst accepting that there will be cases where testing of young children at their parents' request is the best course of action in the circumstances. In the vast majority of cases agreement to defer testing is reached after discussion between the health professionals and the parents. In the rare cases where, after discussion, such agreement cannot be reached, the benefits and harms should be considered, not to reach the "correct" answer, but to assist with balancing the conflicting interests, to ensure that the decision-making process is transparent and that the conclusion reached can be justified.

Where a young person understands the implications of carrier status and clearly consents to testing, with no suggestion that the consent is given under pressure, there are strong arguments for respecting that individual's informed choices and acceding to the request. It is clearly desirable for young people to have their parents' support for such important decisions.

Predictive testing for late-onset disorders

Predictive testing of young children for serious late onset disorders (such as Huntington's Disease) at the request of their parents is very controversial and such requests, although rare, raise serious concerns. There is general agreement that requests for this type of testing in children should be opposed because it would undermine the future adult's right to make his or her own decision about whether to be tested. The very low take-up rate among adults for predictive testing for Huntington's disease suggests that for many people who know they are at risk, the actual or potential harms of testing are perceived to outweigh the benefits. This suggests that many children, as adults, would refuse testing. Testing children, on the basis of parental consent, denies them that option.

There are also major concerns about the effect on the child of knowing that in adult life he or she will develop a severe genetic disorder and that nothing can be done to prevent it. It is feared that learning such news, in childhood or adolescence, could have a very negative effect on the individual's self-esteem and ability to function properly in society. Furthermore, it has been argued that such knowledge would rob the child of a carefree childhood and put additional strain during adolescence when pressures are already great. The confidentiality of the child would also be lost because the parents or adult requesting the test would be informed of the results. There is also a concern that those who find their children to be affected by a late-onset disorder may reflect this in the way they behave towards their children, for example treating them as though they are ill before the disorder becomes manifest or failing to give them encouragement to do well at school or to train for a career. An unfavourable test result might also harm the future life opportunities for the child through disadvantage in employment and insurance.

In view of these concerns, the BMA believes that the child's future right to make his or her own decisions must be respected and that it would not be appropriate to test young children for adult-onset disorders, unless there is an obvious benefit to the child which clearly outweighs the disadvantages. This does not mean that the child should grow up in ignorance of the condition and, in practice, many children grow up with the knowledge that they are at risk of developing a genetic disorder.

With pre-symptomatic testing for adult-onset disorders, where there is no medical benefit, a very high level of capacity would be expected before a young person, under 16 years of age, could give a valid consent. The BMA considers that there are likely to be very few cases where a person under 16 years of age has the requisite capacity to consent to pre-symptomatic testing and recognises that many health professionals will have serious concerns about pre-symptomatic testing of minors regardless of their mental capacity and understanding. Any health professional providing pre-symptomatic testing to a person under 16 years of age must be prepared to justify that decision, on grounds of the individual's competence, and would have a responsibility to ensure that he or she had been given and understood sufficient information, had received extensive counselling, and had considered the implications of a positive test for him or herself and for other family members. The young person should also be strongly encouraged to involve his or her parents or another adult in this important decision. Before proceeding with testing, health professionals should satisfy themselves that an appropriate support mechanism is available for the young person.

3. Summary

- The patient's "best interests" is the paramount criterion in decision making with children and young people. Best interests should be pursued in an holistic manner, taking into account the various physical, emotional, social, cultural and psychological needs of the whole person.

- Once they understand the options, patients are usually the best arbiters of their own interests. Where possible, however, decisions should ideally be family-centred.

- Legally, parents and people with parental responsibility can give proxy consent to procedures which are in the child's interests but cannot validly authorise procedures which are not in the minor's interest. If serious disputes arise in connection with controversial treatments, the courts may have to decide where the child's interests lie.

- Medical interventions may be ethically acceptable when they are neutral. That is to say, even if they are not directly in the child's own interests, they may be permissible if not clearly contrary to those best interests.[42] Informed parental consent, and wherever possible the child's own agreement, are required in such cases.

- Confidentiality is an important principle but is not absolute. The degree to which any patient's privacy is respected depends on the implications of doing so both for that person and for others. Establishing a trusting relationship is an important step which affects patients' long-term attitudes to health professionals but secrecy cannot be promised if serious harm is likely to result.

- Doctors must monitor closely whether the outcomes from their treatment patterns fall below the success rate gained by other practitioners. If so, attention needs to be given urgently to investigating the reasons for this.

- Where doctors modify a standard procedure or introduce a new treatment, they should inform patients and their parents of the reasons and whether there are foreseeable variations in the risks involved. Once success rates of a new procedure appear hopeful, a formal research protocol should be drawn up for appraisal by a research ethics committee. Doctors should not continue indefinitely with an innovative procedure which has not been tested against standard options.

- Any intervention or research whose goal is not that of directly benefitting the child must carry no more than minimal risk; it must not entail pain for the child; informed parental and LREC agreement must be obtained and the child should not be included contrary to his or her wishes.

- Views about what constitute sensitive or controversial procedures change over time. Parental consent is not always sufficient to justify an intervention which does not demonstrably appear to be in the child's own interests. If in doubt, doctors should seek legal advice.

Definition of "Minimal Risk"

Two different ways of assessing risk are mentioned here as useful guides.

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	Negligible	Minimal	More than Minimal
Risk of Death	Less than 1 per million	1 to 100 per million	Greater than 100 per million
Risk of Major Complication	Less than 10 per million	10 to 1000 per million	Greater than 100 per million
Risk of Minor Complication	Less than 1 per 1000	1 to 100 per 1000	Greater than 100 per 1000

Assessment of risk when children participate in research.

Minimal (the least possible) risk describes procedures such as questioning, observing and measuring children, provided that procedures are carried out in a sensitive way, and that consent has been given. Procedures with minimal risk include collecting a single urine sample (but not by aspiration), or using blood from a sample that has been taken as part of a treatment .

Low risk describes procedures that cause brief pain or tenderness, and small bruises or scars. Many children fear needles and for them low rather than minimal risks are often incurred by injections and venepuncture.

High risk procedures such as lung or liver biopsy, arterial puncture, and cardiac catheterisation are not justified for research purposes along. They should be carried out only when research is combined with diagnosis or treatment intended to benefit the child concerned.

1. DoH guidance published 1991. Update according to latest DoH guidance when published.

2. This argument is explored in detail in relation to genetic testing of incompetent adults in the BMA's publication Human Genetics: Choice and Responsibility, 1998.

3. British Paediatric Assn, 1980; Nicholson 1986. (Full refs to be added).

4. The BMA has published a guidance note on ethical issues in paternity testing.

5. Guidance has been published by the Royal College of Paediatrics and Child Health, full refs to be added.

6. Montgomery J. *Health care law*, op cit: 298.

7. *Practice note (Official Solicitor: sterilisation)* op cit: 222.

8. Paraphrased from *Practice note (Official Solicitor: sterilisation)* op cit: ?.

9. Add refs to Australian studies

10. *Re B (A minor) (Wardship: sterilisation)* [1987] 2 All ER 206.

11. *Ibid.*, 206.

12. *Re Y (mental patient) (Bone marrow donation)* [1997] {Get Ref}

13. *Ibid.*, ?. {Get Ref}

14. *Re O* [1993] 2 FLR 149. *Re S* [1993] 1 FLR 376 ??? Re R [1993] [Get Refs}

15. See for example, Pansier F-J, The Legal Relationship of the Patient and Physician in Bloodless Surgery, in Bloodless Surgery: Surgical and Anaesthetic Aspects, Legal and Ethical Issues (1997), Arnette Blackwell SA, Paris.

16. Add full contact details of JW Hospital Liaison Committee.

17. Add ref to Gillick

18. See for example, Walsh P (1999), The vegetative state: persisting problems in law and regulation, King's college London, which summarises European guidelines on this issue as well as recent American literature.

19. The permanent vegetative state, Review of a working group convened by the Royal college of Physicians and endorsed by the Conference of Medical royal Colleges and their faculties of the UK, J. Royal College of Physicians, vol 30, no.2, March/April 1996.

20. RCPCH, Withholding or Withdrawing Life Saving Treatment in Children: A Framework for Practice.

21. British Medical Association. *Withholding and withdrawing life-prolonging medical treatment: Guidance for decision making*. London: BMJ Books, 1999:54.

22. *Airedale NHS Trust v Bland* [1993] 1 All ER 821.

23. *Guidelines for the Ethical Conduct of Medical Research Involving children*, British Paediatric Association, London, August 1992.

24. MRC, The Ethical conduct of Research on Children, 1991 (reprinted 1994)

25. S v S, W v Official Solicitor [1972] AC 24.

26. MRC guidance on this issue closely echo those of other responsible bodies, including the Department of Health.

27. R V Cambridge HA, ex p. B, [1995] 2 All ER 129-138.

28.RCPCH, Medicines for Children, 1999.

29. *Re F (Specific Issue: Child Interview* [1995] 1 FLR 819; *Re M (Care: Leave to Interview Child)* [1995] 1 FLR 825

30. *Child Protection: Medical Responsibilities*: *Guidance for Doctors working with Child Protection Agencies*,

31. See for example, Working Together Under the Children Act 1989 and Working Together to Safeguard Children, add full refs.

32.*Re CS (Expert Witnesses)* [1996] 2 FLR 119

33. (*D v D (County Court: Jurisdiction: Injunctions)* [1993] 2 FLR 802)

34. *South Glamorgan County Council v W and B* [1993] 2 FLR 559

35.This is taken from the 1994/5 Report of the Children Act Advisory Committee (1996) which summarises some of the most important points.

36. In this chapter, we do not discuss illegal procedures such as female genital mutilation. The BMA has a guidance note on FGM, available on request.

37.Add ref

38. A joint guidance note on this issue has been published by the BMA, RCGP, FPA and Brook Advisory Centres.

39. In such cases, the court's permission is required.

40. Re P (a Minor) (1981) 80 LGR 301.

41. Re B (Wardship: Abortion)[1991] 2 FLR 426.

42. MRC guidance on research on children, 1992.

Chapter 8: Health care in schools

The purpose of a school health service is:

- to achieve the best possible level of health (mental and physical) and social well being, current and future for all children of school age; and
- to work in partnership with children, parents and teachers to enable children to benefit fully from education.[1]

It is usually the school nurse who is the central figure in the school health service. The health services' activities include: child health surveillance; health promotion; health interview; liaison with parents, teachers and others involved in the child's care; child protection; immunisation and self referral or 'drop in sessions', particularly in secondary schools.[2] Links with local GPs and practice nurses can ensure that children receive integrated and seamless care at school.

Services, particularly those for young children, have been criticised in the recent past, however, for providing poor access to health professionals, poor opportunities during consultations for children to raise issues and a lack of consent for routine examinations.[3] Research undertaken in 1994 showed that in only around half the schools questioned were the respondents aware of formal procedures for sharing information between the school health service, teaching staff and parents.[4] Although over the last few years there has been a trend towards more proactive services which better recognise the rights of children, improvement is hampered by a lack of resources and facilities.

Awareness by health services and local authorities of these potential problem areas can lead to improvement. Steps should be taken to ensure that the service's accommodation is appropriate for the provision of confidential health services, for example. Health professionals should look for signs that children want to raise issues in consultations, and seek to involve both children and their parents. Lay and professional staff, local authorities and governing bodies should work together on local protocols regarding sharing of information, and to ensure that contracts of employment reflect professional obligations. The BMA has worked with other bodies representing community health practitioners and published a document presenting an idealised view of the school health service, describing what is achieved in the best centres and what can be achieved with drive, commitment, enthusiasm and the support of primary care. It recommends recognising the specialist nature of the school health service, improving the quality and take up of training and developing close working relationships with psychologists, paediatric nurses, dieticians, speech therapists, physiotherapists and social workers.

The BMA finds that dilemmas in schools are most common where lay staff ask health professionals to act contrary to their professional obligations or to take on a role other than providing health care. Evidence from the Royal College of Nursing reveals nurses whose contracts of employment have tried to require them to disclose information about all consultations to the school's head teacher. Health care staff are also sometimes asked to become involved with screening children for evidence of drug misuse. The BMA receives a number of enquiries about the provision of health services in schools, and this chapter draws together the Association's views on the issues. The following sections address these and other potential areas of difficulty or misunderstanding, and offer some guidance. Health professionals may also seek advice from professional, regulatory and indemnifying bodies.

8.1 Confidentiality

The duty of confidentiality which a health professional owes to children, including those living away from the family home at residential schools, is as great as that owed to any other person.[5] That duty may only be breached where there is an overwhelming reason to do so, for example if the child or another person is at grave risk of serious harm if information is not disclosed. Where there is a need to disclose, the child concerned should be encouraged to agree to the disclosure, and there should be discussion about what information needs to be disclosed, to whom, why and what might happen as a result. Only if discussing disclosure with the child would itself cause serious harm might it be justifiable to disclose information without the child's knowledge or consent. Such situations are rare.

Efforts should be made to promote the message about confidentiality to all children and young people. There is evidence to show that the major deterrent to young people asking for sexual health advice from their family doctor is anxiety about confidentiality, particularly where the doctor has close contact with other family members.[6] Such fears might be shared by children thinking about accessing a school health service if they believe disclosure to teaching staff or parents is routine. The BMA recommends that general practices should improve awareness about the duty of confidentiality amongst younger patients. Schools too have an ideal environment in which to provide information to children and should do so in an accessible way which explains their role and their duty of confidentiality.

In schools, it is usually the case that parents and relevant teaching staff are informed where any accident or injury occurs. Some such incidents will be immediately apparent to teachers in contact with the child, who may take the responsibility for informing parents. It has been argued that health professionals should not be expected to keep confidential health information which would be apparent to parents if the child was living at home. For example, if a child suffers an injury which is visible to anybody who comes into contact with him or her, it could be argued that the fact of injury is not confidential. Professional guidance states, however, that doctors must not disclose any personal information about their patients which they learn during the course of professional duties.[7] Clearly a balance needs to be struck between common sense and preserving trust, and in most cases children will be willing to allow their doctor to contact their parents. Where they are not, children should be aware that teaching staff are likely to contact parents in the case of immediately apparent illness or injury.

In addition to keeping parents informed, people with parental responsibility have a statutory right of access to their child's health records in certain circumstances.[8] This includes the records of the school health service. Where the child is capable of giving consent to parental access, it can only occur with that agreement. If the child lacks the necessary capacity, access can be given if it is in the child's best interests. Information previously given in the expectation that it would be kept confidential should not be revealed, nor should the results of investigations or examinations which the child thought were confidential at the time they were conducted. Access to records is covered in greater detail in chapter 3.

8.1.1 Inspection and monitoring standards

Schools are inspected to monitor the standards achieved by children and the quality of learning and teaching. Problems may arise if inspectors wish to see records maintained by schools which contain health information. For example, teachers may keep records relating to the physical or mental health of students if it is relevant to the provision of education. Health professionals working in schools should ensure that lay staff are aware of the sensitive nature of health information and the need to keep it confidential as far as possible.

Teachers and carers should be encouraged to resist passing personal health information to inspectors. Whilst there may be grounds for confirming, for example, that schools are keeping records of health information necessary to support teachers' abilities to meet children's educational needs, it would generally be inappropriate to pass details of such records to inspectors. If external investigations of standards of health care are needed, parents and children should be informed of this and consent for access sought. Only in the most exceptional of circumstances, for example to prevent serious harm to others, should a refusal to allow access be overridden.

The GMC also requires doctors to monitor and maintain awareness of the quality of care being provided.[9] This should include taking part in regular and systematic clinical audit. Where doctors are working alone with schools, it may be helpful to involve colleagues from other schools or the doctor's own practice in audit using anonymous data. As in all areas of practice, patients should be generally aware that audit is carried out, and be told of their right to refuse to allow their information to be used for this purpose.

8.1.2 Disclosure of information to schools

The BMA has received enquiries from GP surgeries about the disclosure of information to schools. It is an inappropriate breach of confidentiality for practices to reveal (without appropriate consent) whether or not a young person had an appointment on a particular day to check whether he or she was playing truant.

8.2 Consent

Being resident away from the parental home does not alter who can, in law, authorise or refuse treatment on behalf of a child. Competent young people, those with parental responsibility and a court may authorise a doctor to provide medical treatment, and, as chapter 2 has shown, any person who has care of a child may also do "what is reasonable in all the circumstances of the case for the purpose of safeguarding or promoting the child's welfare".[10] This includes giving consent to necessary medical treatment, but is unlikely to cover non-urgent or prophylactic medical interventions.

8.2.1 Consent to School Medical Examinations

School medical examinations are an essential part of the health service's role in preventive medicine. Examinations are carried out when children first enter school at age 5, again at age 13 or 14, with opportunities for general health checks between these times.

The form of consent required in order to carry out a routine medical examination of primary school children may raise dilemmas. Throughout this book the importance of involving parents in health care has been stressed, and it would be unfortunate if it became in any way routine for children to be seen in school without consent from parents. For medical assessments, the presence of parents provides a good safeguard, although this must be viewed together with the right of young people to confidentiality and to give consent for themselves.[11]

8.2.2 Implied consent for immunisation

Consent can be taken to be implied when patients (or those giving consent on behalf of children) understand what is being proposed, understand that they have a right to refuse and make no objection. In recent years, immunisation campaigns in some areas have been undertaken on this basis, with parents being given the opportunity to 'opt-out' rather than being required to give explicit consent. Clearly implied consent is only valid if one can be sure that the person concerned has definitely seen and understood the relevant information. Where there is any doubt, additional efforts should be made to ensure that there is no objection. Due to the emphasis the BMA puts on the role of parents in health care, the Association recommends that they should always be informed when immunisation is being carried out, and invited to give their permission. It may be ethically and legally justifiable, however, to proceed without their knowledge or consent where a competent child gives valid consent.

As well as consent from parents, the nature and purpose of the immunisation should be explained to all children who should be invited to agree. If competent young people refuse, doctors should consider whether the benefits to the child of having the immunisation outweigh the harm of overriding a competent refusal. This will involve discussion with parents and the young person, to see whether a compromise solution can be reached. Some children may refuse because they don't want their friends to see them cry, for example. Having the immunisation outside school hours, or at their GP surgery might be acceptable alternatives for these children. As previous chapters have discussed, doctors are unwilling to impose treatment on competent children who refuse unless there is good reason. The BMA believes that there is a strong moral imperative to respect a competent refusal where doing so does not have serious consequences for the health or wellbeing of the child. There has been no guidance from the courts on this matter, as there has been no reported legal case dealing with refusal of elective or prophylactic intervention.

General consent for immunisation is sometimes sought from parents when their child begins boarding school. The Medical Officers of Schools Association (MOSA) suggests a standard consent form which parents sign indicating agreement "that the school medical officer may carry out such immunisations against tetanus, poliomyelitis, measles, mumps and rubella

(German measles) as he deems necessary".[12] While discussion of these matters can be useful to ascertain parents' general views on immunisations, children should still be asked for consent and further discussion will be needed where a young person refuses. Parents should also understand that their decision when children first go to school is not immutable and that they should contact the school health service if their views change.

8.3 Medicines

Many children require the routine use of medicines, such as reliever inhalers for asthma, insulin for diabetes or rectal diazepam for epilepsy. Where there is no health professional providing cover throughout the whole school day, this raises questions of who is responsible for administering the medicines, and the responsibilities of teaching staff or other lay staff if children administer them themselves. It is desirable for children with long term recurring health problems such as these to be accommodated within school so that their education is not disrupted. For this to be done, however, proper and clearly understood arrangements for administration of medicines must be made. Parents should be encouraged to provide maximum support and assistance in helping the school accommodate the pupil, and jointly with the head teacher should reach agreement on the school's role in helping with the child's medical needs.

Teachers have a professional duty to safeguard the health and safety of pupils and a general legal duty of care, but conditions of service do not include any legal or contractual obligation to administer medicine or to supervise a child taking medicine.[13] Teachers may be willing to do so, however, with support, guidance and training from the school health service or other appropriate health professional.[14] The BMA recommends that local authorities should formulate protocols for good communication to facilitate this.[15] Teachers and employers should have regard to their potential liabilities in such circumstances.

Children, their parents, teachers and health professionals should work together to establish the best way to meet a child's needs. This would include measures such as self administration or parental supervision. It is helpful if doctors can prescribe for children so as to avoid the need for medicines to be given during school hours. For example parents can be advised that medicines which need to be administered on a twice daily basis should be given out of school hours. Where administration at school is unavoidable, it is good practice to encourage even young pupils to manage their own medication where they can be trusted to do so.[16] Wherever possible, practical solutions should be sought to ensure the best possible care for the child, without imposing unnecessary burdens on staff.

Guidance for schools on the storage and administration of medicines in schools is available from the Department for Education and Employment and Department of Health.[17] It provides practical suggestions for keeping medication so that it is readily accessible but only to authorised individuals. The advice includes the following:

- Pupils must have access to their medicine when required.

- Schools should not store large volumes of medication. Wherever possible, children should bring in the dose they require each day.
- Stored medicines should note the name of the pupil, name and dose of the drug and frequency of administration. The head teacher is responsible. Pupils should know where their own medication is stored and who holds the key. Medication which pupils may require urgently, such as asthma inhalers should not be locked away.
- Schools should not dispose of medicines. Parents should collect medicines held at school at the end of each term, and are responsible for their safe disposal when necessary.
- All school staff should be familiar with and follow precautions for hygiene and infection control.

The guidance also stresses the importance of discussing management of illness with parents, and seeking their consent to teachers administering medication to children. Individual care plans should be drawn up for children who require support at school, which should take account of the child's own ability to manage their health. The head teacher, parents, child, class teacher, care assistant, support and other school staff, school health service, the GP and any other health professionals involved in the child's care may all need to contribute to a plan.

Where teaching staff are willing to administer or supervise the administration of medicines:

- The employer should arrange appropriate training in conjunction with the health authority;
- Staff should understand and respect the need for confidentiality;
- There should be support mechanisms in place so staff can call on a named professional for advice;
- Local policies should require the presence of two members of staff for the administration of intimate or invasive treatment, at least one of whom should be the same gender as the child.

8.4 Drug misuse

Statistics show a steady increase in the use of illegal drugs amongst school age children.[18] As a measure to combat this, throughout the UK drug education is provided in schools, although this is controversial and there has been little rigorous evaluation of its impact to date.[19] Some schools, predominantly in the independent sector, have also introduced drugs testing policies, and these are the subject of increasing enquiry to the BMA.

Where schools do offer or require testing, it is essential that both students and their parents are aware of this. They should be clear in advance when testing might be provided, and that decisions about whether to undergo testing (and whether to share the results with their parents) will lie with competent young people. At the same time, information should be provided about why the school offers testing, and policies should emphasise that it is part of the educative process and not something carried out for punitive purposes.

In response to this move by the independent sector, in 1995 MOSA issued guidelines for testing for substance misuse in schools.[20] A number of key points from this guidance are summarised below.

- Wherever possible, the school health service should be outside the testing process. This respects its caring and supportive role. The collecting officer should be an outsider paid a retainer by the school to undertake this specific task.
- MOSA considers random testing of young people to be unethical. Testing should be where there is cause to suspect the individual is misusing drugs.
- Written informed consent should be obtained for the collection and testing of samples. Even where young people have the competence to give consent themselves, it is desirable that parents are aware that testing is taking place.
- The results of tests are confidential and should not be disclosed beyond the school authority requiring the test.
- Clear policies should be in place regarding how to deal with results, including practical strategies for ensuring abstinence.

8.5 Summary

Although difficulties may be exacerbated when children are away from home, or in the care of others, the general principles regarding consent and confidentiality are the same. The BMA recommends that parents are informed and involved to the fullest extent possible, whilst respecting the rights and confidences of young people. As is emphasised throughout this guidance, partnership and communication are essential elements to successful health care in schools and residential settings.

1. British Paediatric Association. *Report of a joint working party on health needs of school age children*. London: BPA, 1995.

2. Royal College of Nursing. *Health needs of school age children. An RCN briefing paper*. London: RCN, 1996.

3. Mayall B. *Children, health and the social order*. Buckingham: Open University Press, 1996.

4. Social Science Research Unit. *Health in primary schools: report on a postal questionnaire*. London: SSRU, 1994.

5. Further advice on confidentiality is available in BMA, Brook Advisory Centres, Family Planning Association, Health Education Authority & Royal College of General Practitioners. *Confidentiality and people under 16*. London: BMA, 1993 and BMA. *Confidentiality and disclosure of health information*. London: BMA, 1999.

6. {Add ref to Brook research}

7. General Medical Council. *Confidentiality*. London: GMC, 1995.

8. Data Protection Act 1998. {Check provisions}

9. General Medical Council. *Good medical practice*. London: GMC, 1998: 4.

10. Children Act 1989 s3(5).

11. British Paediatric Association. *Report of a joint working party on heath needs of school age children*. London: BPA, 1995.

12. Medical Officers of Schools Association. *Handbook of school health 18th edition*. Stoke-on-Trent: Trentham Books, 1998: 310.

13. National Union of Teachers. *Medicines in schools: Session briefing*. {date?}

14. DES Circular 11/90. *Staffing for pupils with special educational needs.*.

15. British Medical Association Community Health Doctors Subcommittee. *Medication in schools*. London: BMA, 1994.

16. Department for Education and Employment, Department of Health. *Supporting pupils with medical needs*. London: DfEE, 1996.

17. Department for Education and Employment, Department of Health. *Supporting pupils with medical needs*. London: DfEE, 1996.

18. British Medical Association. *The misuse of drugs*. Amsterdam: Harwood Academic Publishers, 1997: 14-15.

19. British Medical Association. *The misuse of drugs*. Amsterdam: Harwood Academic Publishers, 1997: 31.

20. Medical Officers of Schools Association. *Handbook of school health 18th edition*. Stoke-on-Trent: Trentham Books, 1998: 133-5.

Chapter 9: Summary

This summary is not designed to be read in isolation from the rest of the book. It is intended to highlight some of the main points as an *aide-mémoire.*

9.1 Ethical issues

9.1.1 The patient's "best interests" is the paramount criterion in decision making with children and young people. Best interests should be pursued in an holistic manner, taking into account the various physical, emotional, social, cultural and psychological needs of the whole person.

9.1.2 Once they understand the options, patients are usually the best arbiters of their own interests. Where possible, however, decisions should ideally be family-centred.

9.1.3 Children and young people should be kept as fully informed as they wish and as is possible about their care and treatment. They also have a right to exempt themselves from some aspects of decision making although they should be encouraged to make their general preferences known.

9.1.4 The wishes and values of children and young people should always be sought and taken into account. The individual's overall welfare should be the paramount consideration and listening to minors' views is conducive to promoting their welfare in the widest sense.

9.1.5 The multi-faceted needs, including emotional needs, of children should be recognised.

9.1.6 Children and young people should be encouraged to make all those decisions which they feel comfortable and able to make. In the majority of cases, young people who have an understanding of what is involved can make responsible and reasoned decisions about medical treatment options.

9.1.7 Although minors should be treated in such a way as to promote their personal responsibility consistent with their needs, they should also be encouraged to take decisions in collaboration with other family members, especially parents, if this is feasible.

9.1.8 Wherever possible, decision making should not be hurried and patients given full opportunity to reflect, obtain more information and discuss the options in a supportive environment.

9.2 The law

9.2.1 A doctor may provide treatment for a person under 18 provided that there is valid consent from at least one of:

- a competent child;
- a person or local authority with parental responsibility; or
- a court.

9.2.2 With such a consent, a doctor will be protected from a charge of battery, even if one of more of the above refuse consent. It does not, however, exclude liability for negligence.

9.2.3 Thus the refusal of even a competent person under 18 may be overridden by somebody with parental responsibility or a court.

9.2.4 Children under 16 are competent to give consent to medical treatment if they have sufficient understanding and intelligence to understand what is being proposed.

9.2.5 Between 16 and 18, young people are competent to give consent if they understand in broad terms the nature and effects of the proposed treatment. There is a rebuttable presumption in law that young people have this competence.

9.2.6 Just because consent has been given by someone or a court, does not mean that it is necessarily in the child's best interests for the treatment to be given. Doctors have obligations over and above the requirement to obtain valid consent and must weigh the benefits of providing the treatment against the harm caused by overriding a competent child's refusal.

9.2.7 The moral imperative to provide treatment against a young person's wishes is greater where the treatment aims to prolong or significantly enhance life.

9.2.8 Where consent is unavailable, for example in an emergency and the patient is unable to communicate wishes, or, in the case of children, where nobody with parental responsibility is available, it is lawful for doctors to proceed with treatment necessary to preserve the life, health or well being of the patient.

9.2.9 These principles are the same when the child is resident away from the family home.

It has been suggested that a flow chart should be included to illustrate the legal issues. Examples of flow charts from other publications will be tabled at the meeting. Does the group think this would be helpful?

9.3 Confidentiality

9.3.1 Children and young people are entitled to medical confidentiality on the same grounds as other patients.

9.3.2 This means that their rights are not absolute but can only generally be overridden when there is a clear justification, such as the risk of significant harm to other people. Where there is an exceptional reason justifying disclosure without consent, children should be told that their secrets cannot be kept. In the absence of any such reason justifying disclosure, they should be encouraged but not forced to share their health information with parents.

9.3.3 People with parental responsibility have a statutory right of access to their children's health records where the child is unable to give consent and disclosure would not be contrary to the child's interests.

9.3.4 Competent young people control access to their own health records.

9.4 Competence

9.4.1 Competence is function specific. Doctors must therefore be aware of the task in hand when considering a young person's competence to make a decision.

9.4.2 Whilst some children clearly lack competence due to immaturity, doctors should not judge the ability of a particular child on the sole basis of his or her age.

9.4.3 Doctors should provide a child with as much information about the illness and prognosis as is appropriate for that child.

9.4.4 Doctors should take steps to enhance the ability of children to participate, and encourage them to do so.

9.5 Withdrawing and withholding treatment

9.5.1 There is no obligation on health professionals to provide medical treatment which cannot achieve its clinical aim, or which does not provide an overall benefit to the child.

9.5.2 In deciding whether treatment should be begun or stopped, health professionals must act within the law and will take the lead on assessing the relevant clinical factors.

9.5.3 Decisions about best interests more broadly will be made by families, with the influence of the views of young people growing with their maturity and understanding of the decision.

9.5.4 Support for the child, family and health care team is essential throughout the process of deciding about the provision of life-prolonging treatment, and during and following its implementation.

9.5.5 Constant review of the child's condition is essential, and all decisions and changes to the child's circumstances should be documented in the medical record.

9.5.6 All efforts should be made to overcome disagreements about treatment. Decisions about whether treatment should be offered to a child and his or her family are commonplace. Assessment of the benefits a treatment is offering and balancing potential benefits in the light of the wishes of children and their families is a part of routine practice. The decisions become particularly difficult where the benefits and burdens are finely balanced, for example where there is a very slim chance that a very invasive treatment will give some chance of improvement in a serious condition, or when agreement about how to proceed cannot be reached by the family and health care team.

9.6 Refusal of treatment

9.6.1 Although refusal of treatment by competent young people, and by parents, will be very influential, in some cases these will not be determinative. The aim of decision-making here is to achieve consensus amongst all involved with decisions about care, and in the rare cases where this cannot be achieved despite all efforts, it may be necessary to ask the courts to intervene.

9.6.2 Providing treatment to a competent young person against his or her wishes may require the approval of a court, particularly if providing it requires the use of restraint or containment.

9.6.3 The harm caused by violating a competent child's choice must be balanced against the harm caused by failing to treat.

9.7 Mental disorder

In mental health care:

9.7.1 care should be consensual wherever possible and respect patient autonomy;

9.7.2 minors' views should always be taken into account;

9.7.3 the provision of information and effective communication should be emphasised;

9.7.4 all patients should be as involved as possible in developing their own care plan;

9.7.5 care and treatment should be non-discriminatory and respect diversity;

9.7.6 care should be provided in the least restrictive setting possible;

9.7.7 treatment should involve the least possible segregation from family, friends, school;

9.7.8 where possible, families should be involved in decisions about therapy;

9.7.9 where patients are required to comply with a care regime, they must be provided with

9.7.10 all the services specified in their care plan;

9.7.11 informal care should be considered before recourse to compulsory care;

9.7.12 treatment should be evidence based.

9.8 Sensitive or innovative procedures

9.8.1 Legally, parents and people with parental responsibility can give proxy consent to procedures which are in the child's interests but cannot validly authorise procedures which are not in the minor's interest. If serious disputes arise in connection with controversial treatments, the courts may have to decide where the child's interests lie. Some procedures are sufficiently controversial for the courts to require consent from both parents.

9.8.2 Medical interventions may be ethically acceptable when they are neutral. That is to say, even if they are not directly in the child's own interests, they may be permissible if not clearly contrary to those best interests. Informed parental consent, and wherever possible the child's own agreement, are required in such cases.

9.8.3 Doctors must monitor closely whether the outcomes from their treatment patterns fall below the success rate gained by other practitioners. If so, attention needs to be given urgently to investigating the reasons for this.

9.8.4 Where doctors modify a standard procedure or introduce a new treatment, they should inform patients and their parents of the reasons and whether there are foreseeable variations in the risks involved. Once success rates of a new procedure appear hopeful, a formal research protocol should be drawn up for appraisal by a research ethics committee. Doctors should not continue indefinitely with an innovative procedure which has not been tested against standard options.

9.8.5 Any intervention or research whose goal is not that of directly benefitting the child must carry no more than minimal risk; it must not entail pain for the child; informed parental and LREC agreement must be obtained and the child should not be included contrary to his or her wishes.

9.8.6 Views about what constitute sensitive or controversial procedures change over time. Parental consent is not always sufficient to justify an intervention which does not demonstrably appear to be in the child's own interests. If in doubt, doctors should seek legal advice.

9.9 Further advice

9.9.1 Where there is any doubt, doctors should seek advice from their professional, regulatory and indemnifying bodies.

9.9.2 A list of contact addresses, telephone numbers and websites is given in appendix X.