

## Treatment decisions regarding infants, children and adolescents



Français en page 109

To ensure that the best decisions are made for children and adolescents, these decisions should be made jointly by members of the health care team, the child or adolescent's parents, and sometimes the child or adolescent. Children and adolescents should be involved in decision-making to an increasing degree as they develop, until they are capable of making their own decisions about treatment. End-of-life decision-making, whether or not the child or adolescent is involved, is especially complex.

This policy offers physicians some principles and strategies to facilitate the best possible decisions for their patients. It is not intended to apply to research or to the use of innovative (non-validated) therapy.

### PRINCIPLES/ASSUMPTIONS

- All infants, children and adolescents – regardless of physical or mental disability – have dignity, intrinsic value, and a claim to respect, protection, and medical treatment that serves their best interests.
- Although family issues are important and must be considered, the primary concern of health professionals who care for children and adolescents must be the best interests of individual children and adolescents.
- Decision-making for children and adolescents should be interdisciplinary and collaborative, and should actively involve the family and, when appropriate, the child or adolescent.
- Children and adolescents should be appropriately involved in decisions affecting them. Once they have sufficient decision-making capacity, they should become the principal decision maker for themselves.
- All information presented to patients, families, or the child or adolescent's legal guardian should be truthful, clear and presented with sensitivity. This information should include evidence available in the literature, and the clinical experience of the physician and his or her colleagues.

- A physician's personal and professional values can influence patients and families. The reflective practitioner is aware that personal values should not be allowed to restrict or bias such things as options offered to patients or families.
- The principal obligation of the physician is to the individual patient rather than to society or the health care system. Physicians should act as advocates for their individual patients when scarce resources seem to limit access to care.

### GENERAL PRINCIPLES OF TREATMENT DECISION-MAKING AND INFORMED CONSENT

All decisions are based on a combination of known facts and personal values. In health care, treatment decisions relate to medical information and personal evaluation of this information. For people to make appropriate decisions, they must have the pertinent information, be able to understand how it applies to themselves, and then make a voluntary, or non-coerced, decision. These bases of medical decision-making actually define the three hallmarks of informed choice:

1. Appropriate information: The information necessary to make a decision.
2. Decision-making capacity: The ability to receive, understand and communicate information, and the appreciation of the personal effects of interventions, alternatives or nontreatment.
3. Voluntariness: The decision maker should not be manipulated or coerced, and the option to change one's mind should always be available.

### APPROPRIATE INFORMATION

Whether the principal decision maker is a child or adolescent, a parent, or the child or adolescent's legal guardian, appropriate decisions can be made only with sufficient information. Generally, physicians and other health care

professionals tell patients about their disease, its likely course, the treatment options, the possibility to choose no treatment, the benefits and risks for each option and the likely outcomes, such as length of hospitalization or recovery, scars, and so on. While some patients are content with this amount of information, others may need more information to make a decision.

### DECISION-MAKING CAPACITY

The person with decision-making capacity will not only have the simple ability to understand, but must actually grasp the purpose of the intervention, the consequences of consent or refusal, the alternatives, and the magnitude and probabilities of harm and benefit. An assessment of decision-making capacity for medical treatment is difficult. In everyday terms, a sliding scale may be used: the greater the risk of harm associated with a medical intervention proposed, the greater the demand for full capacity (1). Capacity is not age- or disease-related, nor does it depend on the decision itself, but is a cognitive and emotional process of decision-making relative to the medical decision. The majority of children will not have decision-making capacity and will require a proxy to make decisions for them.

### VOLUNTARINESS

Good health care decisions reflect what each patient thinks is right for himself or herself. However, sometimes patients feel pressured by others, such as other family members or members of the health care team, to make certain decisions. Although other people can offer their views, the final decision should be that of the patient or the patient's proxy.

### PROXY DECISION MAKERS

Adults are usually assumed to have decision-making capacity unless proven otherwise. However, patients who are incapable (eg, because they are unconscious, mentally ill or handicapped, delirious or intoxicated) need a proxy to make health care decisions for them. The same holds true for many, but not all, children and adolescents.

Usually, a family member or a loved one will act as a proxy. There are two types of proxy: substitutes and surrogates. Substitute decision makers know the patient so well as to have already discussed with the patient what he or she would want done; a substitute's role is to promote the patient's expressed wishes. Surrogate decision makers do not know what the patient would want done and are thus charged to decide in the best interests of the patient.

In most cases, parents are appropriate surrogate decision makers for their children and should give primacy to the best interests of their child. However, some older children and adolescents may have the decision-making capacity to make their own health care decisions. In such cases, where a child or adolescent has expressed his or her wishes to the parents, the parents then become substitute decision makers and should respect their child or adolescent's choice.

Although parents usually have the legal and moral authority to act as surrogates for their children or adolescents, this is

not always the case. For instance, parents might not be appropriate decision makers for a child or adolescent in any of the following situations:

- when parents lack decision-making capacity.
- when there are irresolvable differences between parents regarding the child or adolescent's care.
- when parents have clearly relinquished responsibility for the child or adolescent.
- when a legal guardian has been appointed.

Surrogate decision makers must be able to balance the best interests of the child or adolescent with competing interests to maximize benefits and minimize harms. The determination of best interests for a child or adolescent ought to be viewed with careful consideration given to:

- chances of survival;
- the harms and the benefits of treatment;
- evidence regarding long- and short-term medical outcomes of the treatment; and
- long-term implications for the child or adolescent's suffering and quality of life.

The values, preferences, beliefs and expectations of the family also play an important role in decision-making and should not be ignored when considering the best interests of a child or adolescent. Situations may arise in which parents have conflicting interests that affect their ability to choose in the best interests of the patient, eg, considerations for the well-being of other children in the family. These concerns should be acknowledged and addressed sensitively, but the primary focus should be the interests of the patient. To balance competing interests, a standard of 'reasonableness' should apply. This standard asserts that the best option is one that most rational people of goodwill would choose after full consideration of all factors that influence the situation.

There remain conditions in which a child or adolescent's best interests may be unclear, either due to uncertainty about the outcome or about whether the outcome is likely to be beneficial or harmful. In acute situations, and pending clarification of the circumstances, the presumption should be in favour of life-saving or life-sustaining treatment. However, when it is possible to defer or delay acute treatment, such a delay is encouraged while further information is gathered to clarify the issues.

### CLINICAL DECISION-MAKING AND CHILDREN AND ADOLESCENTS

Traditionally, parents and physicians have made all treatment decisions on behalf of children. However, just as the concept of informed choice has developed over the last 30 years, new consideration of children's role in decision-making has evolved (2). While some practitioners believe that children either do not want or are incapable to participate in treatment decisions (3), to deny decision-making

to mature adolescents may be interpreted as a violation of their fundamental rights (4).

#### **APPROPRIATE INFORMATION, VOLUNTARINESS AND CHILDREN AND ADOLESCENTS**

Although neither children nor adolescents may be capable to comprehend all the issues involved in their health care, many have a keen interest in what happens to their bodies. As such, they should be given developmentally appropriate information so that they may understand their situation. However, cultural norms or family values may underlie some parents' reluctance to discuss the child or adolescent's condition, diagnosis or prognosis in his or her presence. While parents' views regarding disclosure are important, the child or adolescent's desire or need for information should remain paramount.

Just as decision-making capacity is a developmental process, so is the ability to make decisions independent from the overt influence and authority of the child or adolescent's parents or health care providers. Nonetheless, not all children and adolescents who are ethically and legally entitled to make their own decisions will want to do so. Indeed, some may not want to receive information about their condition. In this circumstance, it is fair and reasonable to approach the appropriate surrogate for consent.

#### **ASSENT**

Children who have partial skills to make decisions should be recognized as having some authority over their own health care. This can be achieved through the concept of assent whereby children are given both information that they can understand and some appropriate choice in their treatment. An example would be to give a child the choice of arm in which to receive an injection, rather than to give a choice about whether or not to receive the injection. This approach subsumes both voluntariness and age-appropriate information, and demonstrates to the child that he or she is respected as an individual. The use of assent also may improve cooperation with treatment, lessen the child's anxiety, enhance the development of trusting relationships with adults, and improve long-term patient-physician relationships. Care should be taken so that children in these circumstances are not given the impression that they have more control than they do.

#### **DECISION-MAKING CAPACITY AS A DEVELOPMENTAL PROCESS**

Childhood and adolescence are marked by great physical, emotional, psychological and moral development. Just as there are predictable patterns for physical development, the ability of children and adolescents to make personal decisions is tied to cognitive and emotional milestones. As such, paediatric patients fall into one of three groups with respect to appropriate involvement in decision-making (5,6).

#### **INFANTS AND YOUNG CHILDREN**

Preschool children have no significant skills to participate in decision-making in any meaningful way. Therefore, surrogate decision makers should give or refuse permission for treatment on the basis of what they believe to be in the child's best interests.

#### **PRIMARY SCHOOL AGE CHILDREN**

Children of primary school age may participate in medical decisions but do not have full decision-making capacity. Although they may be able to indicate their assent or dissent without fully understanding the implications, this cannot be the final determinant for medical decisions. Children of this age should be provided with information appropriate to their level of comprehension and their assent should be sought. Although the child's parents authorize or refuse treatment, the child's assent should be sought and any strong or sustained dissent should be taken seriously (7). Before treatment is forced on an uncooperative child, consideration should be given to the potential harms of this course of action and all available alternatives. When available, other members of the treatment team – such as child psychologists, child life specialists – may have expertise in gaining the child's trust and cooperation. Some pre-adolescent children, particularly those with much experience with illness, may have enough medical experience and cognitive skills to make their own medical decisions. In these cases, the determination of capacity is a formidable task, but one that must be undertaken and evaluated on the basis of the child's cognitive ability and medical experience.

#### **ADOLESCENTS**

Many, but not all, adolescents are developing the decision-making capacity of adults (8,9). So, just as for adults, adolescents with decision-making capacity will be able to understand and communicate relevant information; think and choose with some degree of independence; assess potential benefit, risk or harms of multiple options, and consider their consequences. Of note, these adolescents should also reflect a fairly stable set of personal values (10). Should any of these important components of decision-making appear to be absent or underdeveloped, extra care should be taken to ensure that adolescents and their families are well-supported in the decision-making process.

#### **EMANCIPATED AND MATURE MINORS**

The concepts of emancipated and mature minors are part of the common law (11). Emancipated minors are no longer dependent on their parents. They may be supporting themselves or living independently from their families. Mature minors are persons who, regardless of their age, are able to understand their health condition, and appreciate the nature and consequences of proposed treatment options. The onus is on the physician to inform and educate these patients in a way that is appropriate to their personal circumstances (eg, development, culture, language), and then assess their understanding of the treatment alternatives and

associated risks and benefits. This is presuming, of course, that the child or adolescent wishes to make his or her own decisions independent from the family.

### CANADIAN LAW

There is considerable variation in Canadian provincial and territorial law about the rights of children and adolescents to provide their own consent to treatment. In some provinces and territories, the age of legal majority is presumed to also be the age of consent. Some provinces stipulate an age of consent, while others follow a process whereby one's right to consent depends on decision-making capacity, rather than age. In all jurisdictions, the "mature minor" principle is relevant. Physicians should be aware of the requirements in their own jurisdiction, and may seek information through hospital risk managers, ethics committees and consultants, and the Canadian Medical Protective Association.

### END-OF-LIFE DECISION-MAKING

The capacity of modern medicine to prolong life is now so advanced that there is concern that the prolongation of life becomes the sole end, irrespective of the harms it may impose. Although the impact on the family – such as the burdens and harms they might experience – must be considered in end-of-life decision-making, these interests should not be allowed to override those of the child or adolescent. It is essential that the decision to use life-sustaining treatment be guided by the best interests of the patient.

### WITHHOLDING OR WITHDRAWING TREATMENT

Some of the principal goals of health care are to maintain life and prevent pain and suffering, and not to unthinkingly prolong the dying process. Exceptions to the general duty to provide life-sustaining treatment may occur when there is consensus that there is a high degree of probability that:

- there is irreversible progression to imminent death;
- treatment is clearly ineffective or harmful;
- life will be severely shortened regardless of treatment, and the limitation or withdrawal of interventions will allow greater palliative and comfort care;
- lives will be filled with intolerable distress and suffering that cannot be prevented or alleviated.

To withhold or withdraw life-sustaining treatment may be ethically appropriate when it is clear that this treatment will not benefit the child or adolescent. Such treatments include aggressive measures aimed at cure, resuscitation, mechanical ventilation, and so on. Decisions to withhold or withdraw antibiotics or artificial nutrition and hydration are more controversial, but may also be considered if they are detrimental to the comfort of the dying child or adolescent (12,13). These difficult and often controversial decisions should not be made in isolation, and should include members of the interdisciplinary team and, when possible

and desired, an ethics committee or consultant. All discussions and decisions to withhold or withdraw treatment should be well documented and reviewed after the child or adolescent's death.

Some families will be comfortable with decisions to withhold or withdraw treatment, while others may take longer to reach this decision. The religious, spiritual, cultural and moral background of families should be recognized in these situations because they frequently influence families and their decisions.

### PALLIATIVE AND BEREAVEMENT CARE

There are no exceptions to the obligation to provide palliative and comfort care, including attention to symptom control and the emotional, psychological, and spiritual needs of the child or adolescent and their family. When the primary goal of treatment becomes palliative, the subsequent care of the child or adolescent and their family should continue to be carried out with the utmost sensitivity, support and compassion. Care of the dying child or adolescent and their family includes the provision of physical and social comfort, and relief of pain and suffering for the child or adolescent through pharmaceutical and nonpharmaceutical modalities (14,15). While the prudent use of sedatives and analgesics is appropriate, to give these drugs with the intent to hasten death is ethically and legally unacceptable. Parents and health care providers who are concerned that the use of analgesics may cause addiction or unintentionally hasten the child or adolescent's death must be reassured that neither of these should occur through judicious treatment.

### CONFLICTS IN DECISION-MAKING FOR CHILDREN

In some situations, conflict may arise if the values and beliefs of parents differ from those of the health care team or even from each other. Although most conflicts involve a remediable breakdown in communication, sometimes a genuine clash in values exists.

Although many parental decisions differ from the recommendations of the health care team, parental decision-making ought to be accepted unless it is obvious to many that the decision is patently not in the best interest of the child or adolescent. Nonetheless, parental authority should be critically scrutinized whenever there is strong disagreement about medical facts, prognosis, risks and benefits of ongoing treatment, and if the child is likely to suffer harm as a result. If disagreement persists, the physician should provide the opportunity for a second opinion, either within his or her own centre or from another centre. Practitioners may not withdraw from a patient's care without providing a referral.

When the physician and health care team believe that parental decisions are clearly inconsistent with the child or adolescent's best interests, the assistance of an institutional ethics committee or ethics consultant is recommended. If this is not available or the conflict is not resolved at this level, then the involvement of local child protection

authorities and the legal system may be unavoidable. Although such a course of action is often uncomfortable for the health care team and should only be used as a last result, its ethical basis rests soundly on the health care professional's duty to ensure that the best interests of the child or adolescent are given primacy.

Among the most sensitive cases are those in which parents refuse to limit treatment that the health care team believes is not beneficial for the child or adolescent. In this situation, if the health care team, an ethics committee or consultant (if available), and an uninvolved medical consultant all agree that treatment is contrary to the best interests of the child or adolescent, a legal opinion may be sought with consideration toward a legal appeal to apprehend medical decision-making for the child or adolescent.

### RECOMMENDATIONS

- Physicians should provide patients and their families with appropriate and sufficient information so that they can participate effectively in decision-making.
  - Physicians should work with other members of the health care team to assist surrogate or substitute decision makers in making decisions that are based on the patient's best interests.
  - Some children and adolescents have the ability and desire to make their own decisions. Physicians should carefully assess these factors, encourage decision-making by patients, families and the health care team together, and support capable patients who wish to make their own decisions.
  - Disclosure of information and inclusion in decision-making should occur according to the stage of the child or adolescent's development. Respect for parental wishes and values is important, and the needs and interests of the child or adolescent should prevail.
  - End-of-life decisions should be made with the comfort of the dying child or adolescent as a constant focal
- point. There are no exceptions to the obligation to provide palliative and comfort care, including attention to symptom control and the emotional, psychological and spiritual needs of the patient and their family.
- In situations of conflict, physicians have an obligation to seek available resources to help resolve that conflict, and to facilitate patients' and families' access to assistance as well.

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The recommendations in this statement do not indicate an exclusive course of treatment or procedure to be followed. Variations, taking into account individual circumstances, may be appropriate.