

4-12-2018

## **Medical decision-making in paediatrics: Infancy to adolescence**

Kevin W. Coughlin

Follow this and additional works at: <https://ir.lib.uwo.ca/paedpub>



Part of the **Pediatrics Commons**

---

## Position Statement

# Medical decision-making in paediatrics: Infancy to adolescence

Kevin W. Coughlin

Canadian Paediatric Society, Bioethics Committee, Ottawa, Ontario

**Correspondence:** Canadian Paediatric Society, 100-2305 St. Laurent Blvd., Ottawa, Ontario K1G 4J8. E-mail [info@cps.ca](mailto:info@cps.ca), website [www.cps.ca](http://www.cps.ca)

### Abstract

Medical decision-making in the paediatric population is complicated by the wide variation in physical and psychological development that occurs as children progress from infancy to adolescence. Parents and legal guardians are the de facto decision-makers in early infancy, but thereafter, the roles of parents/legal guardians and paediatric patients become ever more complex. Health care providers (HCPs), while not decision-makers per se, have a significant role in medical decision-making throughout childhood. This statement outlines the ethical principles of medical decision-making for HCPs involved in caring for paediatric patients. This revision focuses on individual decision-making in the context of the patient–provider relationship and provides increased guidance for dealing with disagreements.

**Keywords:** *Advanced directives; Best Interests; Emancipated minors; End-of-life; Informed consent; Mature minors; SDM*

### BACKGROUND

Western society places a strong emphasis on self-determination and individual patients' rights. This model of autonomous decision-making is operationalized through the informed consent (IC) processes outlined in common law as well as by various forms of health care legislation (1–4). In general, IC requires that a decision maker: 1) has capacity to make the decision, 2) is adequately informed, that is, given all relevant information that a reasonable person would require to make a decision, and 3) the resultant decision must be voluntary and free of coercion.

The first step in this process is often a determination of capacity, specifically: “the patient’s ability to understand information relevant to a treatment decision and to appreciate the reasonably foreseeable consequences of a decision or lack of decision” (5,6). In the paediatric patient, such capacity is either lacking, difficult to determine or varies with age, maturity and the specific situation. Thus, parents and legal guardians are most often the appropriate substitute decision-makers (SDMs) for infants and young children (7). However, providers of paediatric health care are required to make assessments in the context of the patient’s emerging self awareness, developing values and

beliefs, maturing cognitive skills and, where present, provincial/territorial laws determining the age of majority or consent. Their role is complicated by the fact that there is no universally accepted, legally defined age for consent in Canada. Therefore, the capacity of the paediatric patient to consent to a proposed treatment varies with age and circumstances and must be determined on a case-by-case basis.

The second requirement in the IC process requires that a capable decision-maker be given all relevant information that a reasonable person would require to make an informed decision.

The final step is ensuring that the resultant decision is voluntary and free of coercion. The voluntariness of the paediatric patient’s decision often comes into question because of their relatively limited life experience, their dependence on their parents and their emerging sense of self vis à vis spirituality, social identity, etc. When making treatment decisions for an incapable paediatric patient, the primary concerns of health care providers (HCPs) and SDMs should be to maximize benefits, minimize harms and preserve the best-interests of the patient.

A family-centred, shared decision-making model best respects and supports the emerging capacity of the paediatric

patient as well as parental authority and the knowledge and expertise of HCPs.

The participation of children and adolescents in medical decision-making should always be sought, and their involvement should be proportionate with their capacity and circumstances. Their consent, assent or dissent (as defined below) must be respected whenever possible.

When disagreement exists, a stepwise approach that ensures due attention to transparency and process, including consultation should be employed to resolve the conflict.

## CAPACITY IN THE PAEDIATRIC POPULATION

The first step in this care process is the HCP's assessment of a child's or adolescent's ability to understand the particular circumstances relevant to their illness and medical treatment. No universally applicable, validated tool exists in the paediatric world to determine capacity (8).

Infants and preschool children have not yet attained even a very limited definition of capacity. In school-aged children, a developing self-awareness is acknowledged, as is the need for clinicians to respect and nurture the signs of emerging self-determination. Assent should be sought and strong indicators of dissent should be given serious consideration (9–11). Nevertheless, many patients in this age group demonstrate signs of assent or dissent without fully understanding the circumstances driving a particular medical decision. In situations where capacity is not demonstrated, the process of obtaining IC must involve the patient's legal guardian(s) in a family-centred, shared decision-making process that also includes the interprofessional health care team (12). Ultimately, legal decision-making authority rests with the SDM, who is required to act in the best interests of the child.

HCPs have an essential role in communicating treatment-related information to both the child and the SDM(s), promoting assent (where possible) with the child, helping the SDM consider the risks and benefits associated with a proposed decision, and ensuring the best interests of the child are met. HCPs are tasked with recognizing a minimum standard of acceptable care, meaning a treatment course that is beneficial, needed to maintain life or health in a paediatric patient, and below which a SDM is not permitted to act.

Medical decision-making in adolescents is more complicated. While adolescents may demonstrate comparable decision-making capacity to adults in empirical studies (7,8,13–19), their ability to make appropriate decisions are affected—and perhaps impaired—by different psychosocial factors, such as peer pressure, impulsivity and risk-seeking behaviours (20,21). Natural developmental changes that follow from physiologic maturation and integrating life experiences help to reconcile the cognitive

and psychosocial factors involved in decision-making. Similar concerns apply when approaching consent with patients experiencing mental health issues or complex/chronic conditions that make navigating the health care system a priority. The dynamic and progressive nature of capacity makes hard and fast definitions of attainment based on age thresholds impossible in this population. Instead, HCPs, legally and ethically, must ascertain individual patient capacity in case-specific circumstances.

When risks are minimal and the benefits of a proposed therapy are clear, for example, when considering treatment for a local infection, a 14-year-old may have sufficient capacity to understand and consent. But when refusing experimental chemotherapy, the same patient might not have the capacity to reason through the complex issues involved. If the youth is deemed capable and requirements for informed consent are met, authorization of treatment by an SDM is not legally required. When an adolescent's capacity is less certain, invoking the family-centred, shared decision-making model described above may be appropriate.

Common law recognizes the special status of emancipated and mature minors (22,23). Emancipated minors are adolescents who live independently from parent(s) or guardian(s), or who are parents themselves. Mature minors are adolescents who have demonstrated decision-making abilities in other areas of life and, as per the 'mature minor' rule, are: "capable of fully appreciating the nature and consequences of medical treatment [and] can give legally effective consent" (24). In some jurisdictions, mature minor status is conferred as part of a formal legal process. In others, the designation is used informally for adolescents who have met the criteria for capacity according to their HCP. Members of Ontario's Consent and Capacity Board have developed basic guidelines for assessing capacity in young people (25). HCPs should be aware of definitions operating in their province or territory. Some jurisdictions define a legal age of majority for consent to treatment (Table 1) (26). Variations among legal statutes regulating health care consent and individual medical situations may lead care providers to seek advice from experts, such as hospital risk managers, ethics committees or legal counsel. A family-centred, shared decision-making approach may support the needs of the child and adolescent most appropriately (14).

## ASSENT AND DISSENT

The concept of assent is essential to recognizing and respecting any young patient's intrinsic value. Children should be provided with developmentally appropriate information and options, such that they know what to expect—and what is expected of them—and can participate, in a developmentally appropriate way, in their own care. For example, a young child should be offered

**Table 1.** Summary of Canadian law regarding age of consent and advance directives\*

Province/Territory	Details of relevant legislation
British Columbia	<p>The age of majority is 19 years. There is no stipulated age of consent for treatment.</p> <p>The <i>Health Care (Consent) and Care Facility (Admission) Act</i> stipulates that all adults (anyone who has reached 19 years of age) are presumed to be capable until the contrary is demonstrated.</p> <p>The <i>Infants Act</i> applies to persons under 19 years of age. Infants can provide consent if capacity is demonstrated. Consent is not valid unless HCPs have also made reasonable efforts to ensure treatment is in a minor's best interests.</p> <p>Adults can give an advance directive unless they are deemed incapable of understanding the nature and consequences of a proposed advance directive. SDMs must be age of majority.</p> <p><i>Health Care (Consent) and Care Facility (Admission) Act</i>, RSBC 1996, c 181 <a href="http://www.bclaws.ca/civix/document/id/complete/statreg/96181_01">http://www.bclaws.ca/civix/document/id/complete/statreg/96181_01</a></p> <p><i>Infants Act</i>, RSBC 1996, c 223 <a href="http://www.bclaws.ca/civix/document/id/complete/statreg/96223_01#part2">http://www.bclaws.ca/civix/document/id/complete/statreg/96223_01#part2</a></p>
Alberta	<p>The age of majority is 18 years. There is no stipulated age of consent for treatment.</p> <p>A patient under 18 years of age is presumed to be without capacity but may also be assessed and determined to be a 'mature minor' and able to give consent to or refuse treatment.</p> <p>Any person who is at least 18 years of age and understands the nature and effect of a personal directive can make a personal directive and is presumed to understand its nature and possible effects. SDMs must be age of majority.</p> <p><i>Personal Directives Act</i>, RSA 2000, c P-6 <a href="http://www.qp.alberta.ca/documents/Acts/p06.pdf">http://www.qp.alberta.ca/documents/Acts/p06.pdf</a></p> <p>Alberta Health Services, 'Consent to Treatment/Procedures Minor/Mature Minors' (PRR-01-03) <a href="https://extranet.ahsnet.ca/teams/policydocuments/1/clp-consent-to-treatment-prr-01-03-procedure.pdf">https://extranet.ahsnet.ca/teams/policydocuments/1/clp-consent-to-treatment-prr-01-03-procedure.pdf</a></p>
Saskatchewan	<p>The age of majority is 18 years. There is no stipulated age of consent for treatment.</p> <p>A person under 18 years of age who is assessed and deemed capable of consenting to treatment (a mature minor) is allowed to make treatment decisions.</p> <p>Any person 16 years of age or more who has capacity to make a health care decision can make a directive. SDMs must be age of majority unless they are a spouse, who then has capacity to make health care decisions.</p> <p><i>Health Care Directives and Substitute Health Care Decision Makers Act, 2015</i>, SS 2015, c H – 0.0002 <a href="http://www.publications.gov.sk.ca/freelaw/documents/English/Statutes/Statutes/H0-002.pdf">http://www.publications.gov.sk.ca/freelaw/documents/English/Statutes/Statutes/H0-002.pdf</a></p> <p>Saskatoon Health Region 'Consent, Informed Consent' (<i>Policy 7311050-002</i>), <a href="https://www.saskatoonhealthregion.ca/about/RWPolicies/7311-50-002.pdf">https://www.saskatoonhealthregion.ca/about/RWPolicies/7311-50-002.pdf</a></p>
Manitoba	<p>The age of majority is 18 years. There is no stipulated age of consent for treatment.</p> <p>It is presumed that persons 16 years of age or more have capacity to make health care decisions and that persons under 16 years of age do not have this capacity, although the latter presumption can be rebutted with evidence to the contrary.</p> <p>Any person having capacity to make health care decisions can make a health care directive. SDMs must be age of majority.</p> <p><i>Health Care Directives Act</i>, CCSM, c H27 <a href="http://web2.gov.mb.ca/laws/statutes/ccsm/h027e.php">http://web2.gov.mb.ca/laws/statutes/ccsm/h027e.php</a></p> <p>Substitute Consent to Health Care <a href="http://www.manitobalawreform.ca/pubs/pdf/archives/110-full_report.pdf">http://www.manitobalawreform.ca/pubs/pdf/archives/110-full_report.pdf</a></p>
Ontario	<p>The age of majority is 18 years. There is no stipulated age of consent for treatment.</p> <p>The <i>Health Care Consent Act</i> stipulates that all persons (including minors) are presumed to be capable (i.e., able to understand treatment information and reasonably foresee consequences) of making treatment decisions.</p> <p>The <i>Substitute Decisions Act</i> presumes that persons 16 years of age or more are capable of giving or refusing consent in connection with their own care, unless there are reasonable grounds to believe otherwise. Findings of incapacity may be appealed to the Consent and Capacity Review Board.</p>

**Table 1.** Continued

Province/Territory	Details of relevant legislation
Ontario (cont'd)	<p>There is no reference to 'advance directives' in Ontario legislation. The <i>Health Care Consent Act</i> recognizes 'wishes', which 'may be expressed in a power of attorney, in a form prescribed by the regulations, in any other written form, orally or in any other manner'. SDMs must be at least 16 years old, unless they are parents of an incapable patient.</p> <p>The <i>Substitute Decisions Act</i> provides for a 'power of attorney for personal care', where a person or persons can be authorized by the grantor to make decisions on the grantor's behalf. SDMs must be at least 16 years old.</p> <p><i>Health Care Consent Act</i>, 1996 c.2 <a href="http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm">http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm</a></p> <p><i>Substitute Decisions Act</i>, 1992 c.30 <a href="http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_92s30_e.htm">http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_92s30_e.htm</a></p>
Quebec	<p>The age of majority is 18 years.</p> <p>Parental or 'tutor' consent is necessary for all minors under 14 years of age. A 'tutor' is appointed to replace the role of parents when it comes to the minor's affairs.</p> <p>A minor 14 years of age or over may consent to care that is or is not required by the minor's state of health. However, parental or tutor consent will be required when the care is not required by the minor's state of health (e.g., cosmetic surgery for non-medical reasons) if the care involves a serious risk to health and could cause serious and permanent side effects.</p> <p>Court authorization is also required when the person able to give consent to a minor's required care is prevented from doing so, or without justification, refuses to do so. Authorization of the court is necessary, furthermore, to submit a minor 14 years of age or older to care that he refuses—except in emergency cases (life is endangered or integrity threatened), when consent of a parent or tutor is sufficient.</p> <p>Anyone 18 years of age or older and able to exercise rights can appoint a 'mandatary', using a document called a 'mandate in case of incapacity'. An SDM (or mandatary) must have reached age of majority and be capable of performing the tasks assigned.</p> <p>Under the <i>Act Respecting End-of-Life Care</i> (in effect as of December 2015) a person of 'full age' (not a minor) who is capable of giving consent to care may specify, in an advance medical directive, what care required by their state of health they consent or do not consent to, in the event that they become incapable of giving consent.</p> <p><i>Quebec Civil Code</i>, Articles 14–18 <a href="http://legisquebec.gouv.qc.ca/en/ShowDoc/cs/CCQ-1991">http://legisquebec.gouv.qc.ca/en/ShowDoc/cs/CCQ-1991</a></p> <p><i>Act Respecting End-of-Life Care</i> RSQ c S-32.0001 <a href="http://legisquebec.gouv.qc.ca/en/showDoc/cs/S-32.0001?&amp;digest">http://legisquebec.gouv.qc.ca/en/showDoc/cs/S-32.0001?&amp;digest</a></p>
New Brunswick	<p>The age of majority is 19 years. There is no stipulated age of consent for treatment.</p> <p>The <i>Medical Consent of Minors Act</i> provides that minors who are 16 years old may consent to medical treatment in the same manner as they would having attained the age of majority. Minors younger than 16 years old may consent to medical treatment if they are capable of understanding the nature and consequences of the treatment and their decision is consistent with their own best interests, continued health and well-being.</p> <p>Any person with capacity to make decisions (i.e., able to understand relevant information and reasonably foresee consequences) may make a health care directive. A person is presumed to have capacity unless the contrary is demonstrated. SDMs must be age of majority unless they are a spouse, in which case there is no age requirement.</p> <p><i>Medical Consent of Minors Act</i> SN.B 1976, c M-6.1 <a href="http://laws.gnb.ca/en/ShowTdm/cs/M-6.1//">http://laws.gnb.ca/en/ShowTdm/cs/M-6.1//</a></p> <p><i>Advance Health Care Directives Act</i>, SNB 2016, c 46 <a href="http://laws.gnb.ca/en/showdoc/cs/2016-c.46">http://laws.gnb.ca/en/showdoc/cs/2016-c.46</a></p>

**Table 1.** Continued

Province/Territory	Details of relevant legislation
Nova Scotia	<p>The age of majority is 19 years. There is no stipulated age of consent for treatment.</p> <p>Any person who has the capacity to make a personal care decision (able to understand relevant information and appreciate reasonably foreseeable consequences) may make a personal directive. SDMs must be age of majority unless the SDM is a spouse or partner, in which case there is no age requirement.</p> <p><i>Personal Directives Act</i>, SNS 2008, c 8 <a href="http://nslegislature.ca/legc/bills/60th_2nd/3rd_read/b163.htm">http://nslegislature.ca/legc/bills/60th_2nd/3rd_read/b163.htm</a></p>
Prince Edward Island	<p>The age of majority is 18 years. There is no stipulated age of consent for treatment.</p> <p>Every person (including minors) capable (i.e., able to understand relevant information and reasonably foresee consequences) may give or refuse consent to treatment.</p> <p>Every person over the age of 16 years who is capable may make a health care directive. Capacity is presumed until the contrary is demonstrated. SDMs must be capable and at least 16 years of age, unless they are the patient's parent.</p> <p><i>Consent to Treatment and Health Care Directives Act</i>, RSPEI 1988, c C-17.2 <a href="https://www.princeedwardisland.ca/sites/default/files/legislation/c-17_2.pdf">https://www.princeedwardisland.ca/sites/default/files/legislation/c-17_2.pdf</a></p>
Newfoundland and Labrador	<p>The age of majority is 19 years. There is no stipulated age of consent for treatment.</p> <p>Under the <i>Advanced Health Care Directives Act</i>, persons 16 years of age or older are presumed to be competent to make health care decisions, while persons younger than 16 years of age are not. These presumptions can be rebutted with evidence to the contrary.</p> <p>A competent person may make an advance health care directive or appoint an SDM. SDMs must be age of majority.</p> <p><i>Advanced Health Care Directives Act</i>, SNL 1995, c A-4.1 <a href="http://www.assembly.nl.ca/Legislation/sr/statutes/a04-1.htm">http://www.assembly.nl.ca/Legislation/sr/statutes/a04-1.htm</a></p>
Yukon	<p>The age of majority is 19 years. There is no stipulated age of consent for treatment.</p> <p>Every person, including minors, who is capable (i.e., able to understand relevant information, reasons, nature, risks and benefits) may give or refuse consent to care. Capacity is therefore presumed unless demonstrated otherwise (i.e., a presumption can be rebutted by evidence of a minor's immaturity).</p> <p>A person is capable of making a directive if they are 16 years of age or older and able to understand the nature and effect of the directive. SDMs must be 19 years of age or older unless they are a patient's parent or spouse.</p> <p><i>Care Consent Act</i>, SY 2003, c 21 <a href="http://www.gov.yk.ca/legislation/acts/care_consent_c.pdf">http://www.gov.yk.ca/legislation/acts/care_consent_c.pdf</a></p>
Northwest Territories	<p>The age of majority is 19 years. There is no stipulated age of consent for treatment.</p> <p>An adult (19 years of age or older) may make a personal directive unless they do not understand the nature and effect of the directive. An adult is presumed to understand the nature and effect of a directive. SDMs must be age of majority.</p> <p><i>Personal Directives Act</i>, SNWT 2005, c16 <a href="https://www.justice.gov.nt.ca/en/files/legislation/personal-directives/personal-directives.a.pdf">https://www.justice.gov.nt.ca/en/files/legislation/personal-directives/personal-directives.a.pdf</a></p>
Nunavut	<p>The age of majority is 19 years. There is no stipulated age of consent for treatment.</p> <p>Under the <i>Guardianship and Trusteeship Act</i>, an adult is a person who is 18 years of age. Until the contrary is demonstrated, every adult is presumed to be capable of making decisions about their own health care, personal care and well-being.</p> <p>There is no reference to 'advance directives' in Nunavut legislation. An interested party who is an adult, however, can apply to court to be appointed as a guardian, with power to make health care decisions for an incapable adult.</p> <p><i>Guardianship and Trusteeship Act</i> SNWT (Nu) 1994, c 29 <a href="https://www.justice.gov.nt.ca/en/files/legislation/guardianship-and-trusteeship/guardianship-and-trusteeship.a.pdf">https://www.justice.gov.nt.ca/en/files/legislation/guardianship-and-trusteeship/guardianship-and-trusteeship.a.pdf</a></p>

HCP Health care provider; SDM Substitute decision-maker

\*Table is based on information in ref. (37). It does not include consideration of consent for minors apprehended under provincial/territorial child welfare/protection legislation.

the choice of where to receive an injection, rather than whether to receive the injection. In many cases, seeking and obtaining assent can reduce patient anxiety, promote trust between patient and HCPs, and acknowledge a patient's developing autonomy. Patient engagement is usually possible without giving the impression that they have more control than they really do (22).

It is assumed, first and foremost, that a child's discomfort and distress is minimized. When this is achieved, the child may still object strongly to a proposed treatment or procedure. This dissent should be recognized and acknowledged. In cases of overt dissent, a careful reconsideration of the medical necessity, risks and benefits of a proposed treatment is an essential step before continuing.

## ROLES AND RESPONSIBILITIES OF THE SDMs

Most preadolescent children need an SDM to act on their behalf, and parents are usually the appropriate SDMs. A legally defined hierarchy of appropriate SDMs is outlined in most provincial/territorial health legislation that HCPs should be familiar with. It should be noted that the authority of SDMs is not absolute. In most jurisdictions, their decision-making authority is limited to interventions deemed to be medically necessary. In cases where medical necessity has not been established or a proposed treatment involves personal preference, intervention should be deferred until individuals are capable of making their own choice (26). Also, SDMs are obligated to act in accordance with the previously expressed wishes of a prior capable patient or, in the patient's 'Best Interests' if those wishes are unknown or nonexistent (1).

## BEST INTERESTS

A starting point for identifying a reasonable treatment decision for an incapable child or youth involves weighing the benefits against the burdens of a proposed treatment in the context of what is known of the patient's values, beliefs, family relationships and cultural norms (27). Caution should be taken in assuming that the SDM always knows what's best for the patient. Take time to explore the reasons behind treatment decisions, especially in cases where high emotional stakes are in play, such as end-of-life care. The use of the Best Interests Standard requires three necessary and sufficient factors: 1) using the best possible information to assess and maximize an incapable patient's long-term benefits and to minimize any corresponding burdens; 2) choices made using this standard must meet a minimum acceptable threshold of care, as judged by the Reasonable Person Standard; and 3) SDMs must act in accordance with accepted moral and legal duties to their ward (28). When significant uncertainty

surrounds a treatment or its outcome, attention should focus on minimizing associated harms. For example, when a cure for a particular condition is unlikely and the treatment is associated with significant harms or burdens, altering treatment goals to provide palliative care and improve quality of life in the time remaining may be an appropriate course.

## FAMILY-CENTRED, SHARED DECISION-MAKING

An emerging body of literature supports a family-centred, shared decision-making model of care in paediatrics (12,26–30). In this Relational Autonomy-based model, the values and beliefs expressed by the patient and family can also be guided by the medical knowledge and experience of HCPs to determine and promote the best possible treatment for an incapable patient. This approach does not replace the primary authority of parents as SDMs. Rather, it acknowledges the expertise and input of health care team members, while supporting decision-making authority within the family. In complex cases, additional discussion and consultation with experts in spiritual care, social work and bioethics add value to the decision-making process and help to ensure that the needs of all participants are met.

## END-OF-LIFE DECISION-MAKING

Advances in medical care have increased the ability to prolong life. However, prolongation of life is not the primary goal of medical care and the use of such technologies must be considered in relation to the risks and benefits they provide to the paediatric patient. Medical decision-making at the end of life should focus on maximizing patient comfort and minimizing associated harms.

## WITHHOLDING OR WITHDRAWING LIFE-SUSTAINING INTERVENTIONS

At some point during the care of a paediatric patient, it may be appropriate to withhold or withdraw life-sustaining interventions. This milestone may be reached when:

- progression to death is imminent or irreversible,
- proposed interventions are ineffective or likely to result in greater harms than benefits, or
- interventions only prolong the dying process, and discontinuing them would allow for better provision of palliative care.

These decisions are always difficult and may be controversial due to their emotionally charged, value-laden nature. However, patients, families and HCPs may yet benefit in different ways from family-centred, shared decision-making. Withholding or withdrawing artificial nutrition and/or hydration may be more controversial than withholding or withdrawing resuscitative measures or artificial ventilation. There are, however,

circumstances in which stopping feeding and hydration may be considered (31). The duty to provide appropriate palliative care and symptom management for the dying patient remains paramount throughout the end-of-life process.

## RESOLVING CONFLICTS

Situations exist in which SDMs and HCPs experience competing interests (e.g., financial constraints, the needs of other family members or scarcity of supportive resources). Deeply held moral, religious or cultural beliefs sometimes contribute to conflict around medical decisions. Ideally, such concerns should be identified and addressed in a respectful manner as early as possible and discussions should be truthful and transparent, always assuming that the primary focus of decision-making remains the patient's best interests (22). Open communication is often key to resolving such issues. Participants should clearly identify the values contributing to conflict and discuss the goals of the proposed treatment. Early discussion around the expectations, limitations and uncertainties of treatment options and outcomes may help establish mutually agreeable treatment plans.

Occasionally, serious disagreements over what constitutes the patient's best interests persist among equally appropriate SDMs or between SDMs and HCPs, even after a collaborative decision-making process is implemented. Some examples include disagreements between parents with joint custody, the wish of HCPs for life-saving transfusion of blood products for a child whose parents refuse based on cultural or religious beliefs (32) or, conversely, the desire of parents or guardians to continue life-sustaining interventions when there is little hope of reasonable recovery. In such cases and if circumstances permit, the proposed intervention should be delayed while an attempt at resolution is made in the current clinical setting (23). This step may involve further discussions and/or referral for a second, independent medical opinion.

Consulting with a spiritual care leader, social worker, patient relations expert, bioethicist or a bioethics committee, or with institutional or personal legal counsel, is often a useful step in complex cases. If the young patient's life is at risk, child welfare or child protection legislation mandates reporting in most jurisdictions. In such cases, consent will be given or withheld by a court. In the event of a true emergency, where time does not permit an HCP to access the options described, the ethical principles of beneficence and nonmaleficence, as well as laws under the emergency doctrine, permit the provision of emergent life-sustaining interventions. In Ontario, for example, application can be made to the Consent and Capacity Board, a quasi-judicial body with limited but growing experience in paediatric consent cases (33). In other jurisdictions, parents, guardians or physicians can request legal intervention. In such cases, securing institutional and personal legal advice is a must. Being truthful and transparent throughout the process is vital to ensuring relations with the family and for meeting the best

interests of the patient. Documentation of the medical situation as it progresses and of all meetings about the child's care must be impeccable and current.

Occasionally, paediatric HCPs consider particular medical intervention(s) to be inappropriate. Practitioners are not legally obligated to provide such treatments. Medical futility is difficult to define, and careful consultation with appropriate medical, legal and ethical experts may be warranted before declaring a treatment option to be inappropriate (34). Once a treatment has begun, it is generally considered to be part of the patient's care plan; any subsequent decision to limit or withdrawal that treatment requires informed consent (35).

An HCP may become involved in conflicts related to scarcity of resources. Allocating organs for transplantation or providing intensive life-sustaining therapies during a pandemic are two practical examples. A detailed discussion of the ethics of priority-setting is beyond the scope of this statement, but as a general principle, the first duty of HCPs is to the patient under care. Decisions around resource allocation are best made in advance, with appropriate representation from those impacted by the decision and following a clearly agreed upon process and framework (36). Paediatric HCPs should be advocates for equitable access for paediatric patients to health care resources in such circumstances.

## SUMMARY

Medical decision-making in paediatrics is complicated by the wide variation in physical and psychological development as patients age. The participation of children and adolescents in health care decision-making should increase in proportion to their developing capacity. Minimizing harm and maximizing the patient's best interests should always be the primary focus of medical decision-making. The following recommendations support those principles.

## RECOMMENDATIONS

- Children's and adolescents' participation in medical decision-making should be sought in proportion to their developmental capacity to understand the nature and consequences of their medical problem as well as to reasonably foreseeable risks and benefits of the treatment proposed.
- HCPs and SDMs should be informed about, and act in accordance with, laws and regulations governing consent to treatment within their jurisdiction.
- HCPs must provide patients and their SDMs with all the information they need to participate effectively in the decision-making process.
- Assent or dissent should both be respected whenever possible; it is also recognized that in the absence of capacity, minimizing harms and maximizing the patient's best interests is the priority.



- HCPs, patients and families should work together to reach medical decisions based on the patient's best interests or outcomes.
- In cases of serious disagreement or competing interests, the HCP's primary responsibility is to the patient.
- In complex social situations, a collaborative process should be agreed upon to clearly identify the SDM(s) in a timely fashion.
- HCPs should be aware of the conflict resolution process in place in their practice environment.
- In situations of conflict, HCPs have an obligation to seek and access resources to help resolve that conflict and to facilitate patient and family access to such assistance as well.

### Recommended resources

Canadian Medical Protective Association. A consent guide for Canadian physicians: [www.cmpa-acpm.ca/en/handbooks/-/asset\\_publisher/TayXf91AzWR2/content/consent-a-guide-for-canadian-physicians](http://www.cmpa-acpm.ca/en/handbooks/-/asset_publisher/TayXf91AzWR2/content/consent-a-guide-for-canadian-physicians)

Royal College of Physicians and Surgeons of Canada, Medical decision-making and mature minors: [http://www.royalcollege.ca/portal/page/portal/rc/common/documents/bioethics/section1/case\\_1\\_5\\_2\\_e.html](http://www.royalcollege.ca/portal/page/portal/rc/common/documents/bioethics/section1/case_1_5_2_e.html)

### Acknowledgements

Special thanks are due to Professor Mary J Shariff, PhD, for her meticulous legal review of this statement, which was also reviewed by the Acute Care, Adolescent Health and Community Paediatrics Committees of the Canadian Paediatric Society.

### References

1. Government of Ontario, Health Care Consent Act, Ontario, 2010. c.1 Sched. 9. [www.e-laws.gov.on.ca/html/statutes/english/elaws\\_statutes\\_96h02\\_e.htm](http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm) (version current January 1, 2017, Accessed February 27, 2017).
2. Peppin P. Informed consent. In: Downie J, Caulfield T, Flood C, eds. Canadian Health Law and Policy, 3rd edn. Markham, Ont. LexisNexis, 2007.
3. Berry RM. Informed consent law, ethics, and practice: From infancy to reflective adolescence. *HEC Forum* 2005;17(1):64–81.
4. Osborne PH. Consent to treatment. In: Irvine JC, Osborne PH, Shariff M, eds. Canadian Medical Law: An Introduction for Physicians, Nurses and Other Health Care Professionals. Toronto, Ont. Thomson Reuters, 2013:34.
5. Etchells E, Sharpe G, Elliott C, Singer PA. Bioethics for clinicians: 3. Capacity. *CMAJ* 1996;155(6):657–61.
6. Williams JR. Consent. In: Singer PA, Viens AM, eds. The Cambridge Textbook of Bioethics. New York, NY: Cambridge University Press, 2008.
7. Harrison C, Kenny NP, Sidarous M, Rowell M. Bioethics for clinicians: 9. Involving children in medical decisions. *CMAJ* 1997; 156(6):825–8.
8. Raymundo MM, Goldim JR. Moral-psychological development related to the capacity of adolescents and elderly patients to consent. *J Med Ethics* 2008;34(8):602–5.
9. Ecoffey C, Dalens B. Informed consent for children. *Curr Opin Anaesthesiol* 2003;16(2):205–8.
10. Baylis F. The moral weight of a child's dissent. *Ethics Med Pract* 1993;3(1):2–3.
11. Van Norman G, Jackson SH, Waisel D. Informed consent: Ethical implications in clinical practice. *Curr Opin Anaesthesiol* 2004;17(2):177–81.
12. Rushton CH, Glover JJ. Involving parents in decisions to forego life-sustaining treatment for critically ill infants and children. *AACN Clin Issues Crit Care Nurs* 1990;1(1):206–14.
13. Zinner SE. The elusive goal of informed consent by adolescents. *Theor Med* 1995;16(4):323–31.
14. Weithorn LA, Campbell SB. The competency of children and adolescents to make informed treatment decisions. *Child Dev* 1982;53(6):1589–98.
15. Lewis CC. How adolescents approach decisions: Changes over grades seven to twelve and policy implications. *Child Dev* 1981;52:538–44.
16. Mann L, Harmoni R, Power C. Adolescent decision-making: The development of competence. *J Adolesc* 1989;12(3):265–78.
17. Ormond C, Luszcz MA, Mann L, Beswick G. A metacognitive analysis of decision making in adolescence. *J Adolesc* 1991;14(3):275–91.
18. Alderson P, Sutcliffe K, Curtis K. Children's competence to consent to medical treatment. *Hastings Cent Rep* 2006;36(6):25–34.
19. Weir RF, Peters C. Affirming the decisions adolescents make about life and death. *Hastings Cent Rep* 1997;27(6):29–40.
20. Diekema DS. Adolescent refusal of lifesaving treatment: Are we asking the right questions? *Adolesc Med State Art Rev* 2011;22(2):213–28, viii.
21. Shariff MJ. The mature minor patient and the refusal of treatment. In: Irvine JC, Osborne PH, Shariff M, eds. Canadian Medical Law: An Introduction for Physicians, Nurses and Other Health Care Professionals. Toronto, Ont. Thomson Reuters, 2013:521.
22. Harrison C; Canadian Paediatric Society, Bioethics Committee. Treatment decisions regarding infants, children and adolescents. *Paediatr Child Health* 2004;9(2):99–103.
23. Traugott I, Alpers A. In their own hands: Adolescents' refusals of medical treatment. *Arch Pediatr Adolesc Med* 1997;151(9):922–7.
24. Osborne PH. The consent of minors. In: Irvine JC, Osborne PH, Shariff M, eds. Canadian Medical Law: An Introduction for Physicians, Nurses and other Health Care Professionals. Toronto, Ont. Thomson Reuters, 2013:44.
25. Tsai E; Canadian Paediatric Society, Bioethics Committee. Advance care planning for paediatric patients. *Paediatr Child Health* 2008;13(9):791–6.
26. Kent CA. Consent. In: Medical Ethics: The State of the Law. Markham, Ont. LexisNexis, Butterworths, 2005.
27. Kopelman LM. The best interests standard for incompetent or incapacitated persons of all ages. *J Law Med Ethics* 2007;35(1):187–96.

28. Carneval FA. The birth of tragedy in pediatrics: A phronetic conception of bioethics. *Nurs Ethics* 2007;14(5):571–82.
29. Payot A, Gendron S, Lefebvre F, Doucet H. Deciding to resuscitate extremely premature babies: How do parents and neonatologists engage in the decision? *Soc Sci Med* 2007;64(7):1487–500.
30. Morrow J. MSJAMA: Making mortal decisions at the beginning of life: The case of impaired and imperiled infants. *JAMA* 2000;284(9):1146–7.
31. Tsai E; Canadian Paediatric Society, Bioethics Committee. Withholding and withdrawing artificial nutrition and hydration. *Paediatr Child Health* 2011;16(4):241–4.
32. Walker C. Makayla Sault, Girl Who Refused Chemo for Leukemia, Dies. *CBC News*, January 18, 2015. [www.cbc.ca/news/aboriginal/makayla-sault-girl-who-refused-chemo-for-leukemia-dies-1.2829885](http://www.cbc.ca/news/aboriginal/makayla-sault-girl-who-refused-chemo-for-leukemia-dies-1.2829885) (Accessed February 27, 2017).
33. Sibbald RW, Chidwick P. Best interests at end of life: A review of decisions made by the Consent and Capacity Board of Ontario. *J Crit Care* 2010;25(1):171.e1–7.
34. Sibbald R, Downar J, Hawryluck L. Perceptions of “futile care” among caregivers in intensive care units. *CMAJ* 2007;177(10):1201–8.
35. *Cuthbertson v. Rasouli*, 2013 SCC 53, [2013] 3 S.C.R. 341. <http://scc-csc.lexum.com/scc-csc/scc-csc/en/item/13290/index.do> (Accessed February 27, 2017).
36. Martin DK, Gibson JL, Singer PA. Priority setting. In: Singer PA, Viens AM, eds. *The Cambridge Textbook of Bioethics*. New York, NY: Cambridge University Press, 2008.
37. Shariff MJ, Hilder VP. Advance directives. In: Irvine JC, Osborne PH, Shariff M, eds. *Canadian Medical Law: An Introduction for Physicians, Nurses and Other Health Care Professionals*. Toronto, Ont. Thomson Reuters, 2013:675.

### CPS BIOETHICS COMMITTEE

**Members:** *Kevin W. Coughlin BScH, MD, MHSc (Bioethics), FRCPC (past Chair), Dawn Davies MD (Chair), Julie Emberley MD, Marie-Claude Grégoire MD, Ian Mitchell MD, Aideen Moore MD, Paul Thiessen MD (Board Representative)*

**Principal author:** *Kevin W. Coughlin BScH, MD, MHSc (Bioethics), FRCPC*