

# Pediatric decision-making: Help parents protect, empower kids

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Parents have the legal responsibility to make medical decisions in the best interests of their minor children who lack decision-making capacity, but they also have the ethical duty to develop that capacity. Ethics policy recently adopted by the AMA recommends ways that physicians should support parents in helping children become independent decision-makers.

This guidance, formalized in an opinion in the *AMA Code of Medical Ethics*, grew out of a 2017 report of the AMA Council on Ethical and Judicial Affairs, which maintains and updates the *Code*. Noting that the “best-interest standard” has long predominated, the report noted that consensus today rests on a more nuanced view of medical decision-making for minors.

“Parents (or guardians) are also recognized to have a responsibility to foster their children’s autonomy and moral growth, a responsibility clinicians share,” the report says. “Providing information in a developmentally appropriate way that respects the minor patient’s cognitive ability, engaging the child in decision-making to the extent possible and seeking the child’s assent to proposed interventions helps to fulfill that responsibility.”

## What the *Code* says

In Opinion 2.2.1, “Pediatric Decision-Making,” the *Code* explains:

As the persons best positioned to understand their child’s unique needs and interests, parents (or guardians) are asked to fill the dual responsibility of protecting their children and, at the same time, empowering them and promoting development of children’s capacity to become independent decision-makers. In giving or withholding permission for medical treatment for their children, parents or guardians are expected to safeguard their children’s physical health and well-being and to nurture their children’s developing personhood and autonomy.

But parents' authority as decision-makers does not mean children should have no role in the decision-making process. Respect and shared decision-making remain important in the context of decisions for minors. Thus, physicians should evaluate minor patients to determine if they can understand the risks and benefits of proposed treatment and tailor disclosure accordingly.

The more mature a minor patient is, the better able to understand what a decision will mean, and the more clearly the child can communicate preferences, the stronger the ethical obligation to seek minor patients' assent to treatment. Except when immediate intervention is essential to preserve life or avert serious, irreversible harm, physicians and parents/guardians should respect a child's refusal to assent, and when circumstances permit should explore the child's reason for dissent.

For health care decisions involving minor patients, physicians should:

Provide compassionate, humane care to all pediatric patients.

Negotiate with parents/guardians a shared understanding of the patient's medical and psychosocial needs and interests in the context of family relationships and resources.

Develop an individualized plan of care that will best serve the patient, basing treatment recommendations on the best available evidence and in general preferring alternatives that will not foreclose important future choices by the adolescent and adult the patient will become. Where there are questions about the efficacy or long-term impact of treatment alternatives, physicians should encourage ongoing collection of data to help clarify value to patients of different approaches to care.

Work with parents or guardians to simplify complex treatment regimens whenever possible and educate parents/guardians in ways to avoid behaviors that will put the child or others at risk.

Provide a supportive environment and encourage parents or guardians to discuss the child's health status with the patient, offering to facilitate the parent-child conversation for reluctant parents. Physicians should offer education and support to minimize the psychosocial impact of socially or culturally sensitive care, including putting the patient and parents/guardians in contact with others who have dealt with similar decisions and have volunteered their support as peers.

When decisions involve life-sustaining treatment for a terminally ill child, ensure that patients have an opportunity to be involved in decision-making in keeping with their ability to understand decisions and their desire to participate. Physicians should ensure that the patient and parents/guardians understand the prognosis (with and without treatment). They should discuss the option of initiating therapy with the intention of evaluating its clinical effectiveness for the patient after a specified time to determine whether it has led to improvement and confirm that if the intervention has not achieved agreed-on goals it may be discontinued.

When it is not clear whether a specific intervention promotes the patient's interests, respect the decision of the patient (if the patient has capacity and is able to express a preference) and parents/guardians.

When there is ongoing disagreement about patient's best interest or treatment recommendations, seek consultation with an ethics committee or other institutional resource.

## More help here

The *Code* features additional guidance on informed consent and shared decision-making for minors, including opinions on mandatory parental consent to abortion, treatment decisions for seriously ill newborns and genetic testing of children.