

OPINION OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS\*

CEJA Opinion 1-A-19

Subject: Amendment to E-2.2.1, “Pediatric Decision Making”

Presented by: James E. Sabin, MD, Chair

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1 INTRODUCTION

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At the 2018 Interim Meeting, the American Medical Association House of Delegates adopted the recommendations of Council on Ethical and Judicial Affairs Report 3-I-18, “Amendment to E-2.2.1, ‘Pediatric Decision Making.’” The Council issues this Opinion, which will appear in the next version of AMA PolicyFinder and the next print edition of the *Code of Medical Ethics*.

E-2.2.1– Pediatric Decision Making

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/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:

- (a) Provide compassionate, humane care to all pediatric patients.
- (b) 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.

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\* Opinions of the Council on Ethical and Judicial Affairs will be placed on the Consent Calendar for informational reports, but may be withdrawn from the Consent Calendar on motion of any member of the House of Delegates and referred to a Reference Committee. The members of the House may discuss an Opinion fully in Reference Committee and on the floor of the House. After concluding its discussion, the House shall file the Opinion. The House may adopt a resolution requesting the Council on Ethical and Judicial Affairs to reconsider or withdraw the Opinion.

- 1 (c) Develop an individualized plan of care that will best serve the patient, basing treatment  
2 recommendations on the best available evidence and in general preferring alternatives that will  
3 not foreclose important future choices by the adolescent and adult the patient will become.  
4 Where there are questions about the efficacy or long-term impact of treatment alternatives,  
5 physicians should encourage ongoing collection of data to help clarify value to patients of  
6 different approaches to care.  
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- 8 (d) Work with parents/guardians to simplify complex treatment regimens whenever possible and  
9 educate parents/guardians in ways to avoid behaviors that will put the child or others at risk.  
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- 11 (e) Provide a supportive environment and encourage parents/guardians to discuss the child's  
12 health status with the patient, offering to facilitate the parent-child conversation for reluctant  
13 parents. Physicians should offer education and support to minimize the psychosocial impact of  
14 socially or culturally sensitive care, including putting the patient and parents/guardians in  
15 contact with others who have dealt with similar decisions and have volunteered their support  
16 as peers.  
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- 18 (f) When decisions involve life-sustaining treatment for a terminally ill child, ensure that patients  
19 have an opportunity to be involved in decision making in keeping with their ability to  
20 understand decisions and their desire to participate. Physicians should ensure that the patient  
21 and parents/guardians understand the prognosis (with and without treatment). They should  
22 discuss the option of initiating therapy with the intention of evaluating its clinical  
23 effectiveness for the patient after a specified time to determine whether it has led to  
24 improvement and confirm that if the intervention has not achieved agreed-on goals it may be  
25 discontinued.  
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- 27 (g) When it is not clear whether a specific intervention promotes the patient's interests, respect the  
28 decision of the patient (if the patient has capacity and is able to express a preference) and  
29 parents/guardians.  
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- 31 (h) When there is ongoing disagreement about patient's best interest or treatment  
32 recommendations, seek consultation with an ethics committee or other institutional resource.  
33 (IV, VIII)