

MLPP News

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Medical-Legal Partnership Project News

FOCUS

Living Wills, Advanced Directives, and End-of-Life Decisions: What are the Minor Patient's Rights?

By Jay Sicklick, MLPP Director

This month's Focus takes a look at end-of-life decisions regarding a minor's care. With all of the recent news surrounding the "right to die," and end-of-life decisions regarding self-autonomy and refusal of care, questions about a minor's role in these difficult areas present unique and distinct challenges. Here are some guidelines to assist the clinician in this complicated area.

What is a living will, and is it different than an "advanced directive?"

A living will is a legal document that states a person's wishes regarding any aspect of her health care, including the withholding or withdrawal of life-support systems. "Advanced directives" are written instructions, such as a living will or durable power of attorney, which are recognized under Connecticut law to express a person's wishes as to her health care if the person is unable to make or communicate treatment decisions. Thus, advanced directives may include a living will or health care instructions, the appointment of a health care agent, the appointment of an attorney-in-fact for health care decisions (also called a durable power of attorney for health care decisions), appointment of a "conservator of the person," and instructions for organ donation.

What are life support systems?

Life support systems mean any medical procedure or intervention

which serves only to postpone the moment of death or maintain the person in a state of permanent unconsciousness. Examples of life support systems include mechanical or electronic devices (ventilators, e.g.) and artificial means of providing nutrition or hydration, such as a feeding tube.

Can a minor execute a valid living will, or other type of advanced directives?

No! Connecticut law, pursuant to Conn. Gen. Stat. § 19a-575, provides that only a person **eighteen years of age or older** may execute a document which contains directions as to specific life support systems which the patient chooses to have administered. This proscription also applies to the execution of the appointment of a health care agent, or the appointment of an attorney-in-fact for health care decisions.

Can a minor who is emancipated pursuant to a valid Connecticut court order execute a legally valid living will or other advanced directives?

This is an open question that has not been resolved by a Connecticut court to date. The statutes governing the execution of a living will and those providing direction for the emancipation of a minor (Conn. Gen. Stat. § 46b-150 *et seq.*) do not specifically answer this question, although emancipated minors have the right to consent to medical care without parental consent, knowledge, or liability. While it is

extremely unlikely that an emancipated minor would have executed a living will prior to becoming "permanently unconscious," it is probable that a physician would take into account any evidence expressed by the emancipated minor as directed by the governing statutes.

What about end-of-life decision making for the unemancipated minor – who gets to make the decisions regarding life support systems, including nutrition and hydration?

This is a complex area where the disciplines of law, medicine and ethics intersect. While each case is different, the guiding principle of law is that minors do not have the legal capacity to direct their care, including end-of-life decision making, on an independent basis. While a minor's parents or legal guardians are the legally responsible decision makers in these cases, the American Academy of Pediatrics consistently opines that minors, as patients, "have a moral and legal right to refuse proposed medical intervention ..." and that "[r]espect for competent patients' autonomy ordinarily extends even to the refusal or discontinuation of their own life-sustaining treatment." *See* 95 Pediatrics 314 (Feb. 1995). Thus, while this area is fraught with legal, moral and ethical dilemmas, clinicians are urged to consult with the appropriate institutional ethics committees, or health law attorneys who demonstrate expertise in this difficult domain.

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Where can I find more information about end-of-life decision making, advanced directives and patient autonomy?

The Connecticut Attorney General's Office provides a detailed overview of the law regarding advanced directives as well as forms that can be downloaded from the Internet at www.cslib.org/attygenl/mainlinks/tabindex6.htm. The best source for information on treatment of adolescents regarding issues of consent, assent, and refusal of treatment can be found in the article "Informed Consent, Parental Permission, and Assent in Pediatric Practice," 95 *Pediatrics* 314 (Feb. 1995), which is available on the KidsCounsel website at www.kidscounsel.org and at the American Academy of Pediatrics' website at www.aap.org. Other questions may be directed to the MLPP Director by calling (860)570-5327, or e-mail jsicklic@kidscounsel.org

We Want to Hear from You!

Submit questions for the next edition of the MLPP newsletter to jsicklic@kidscounsel.org or, call Jay Sicklick at 860-570-5327. For information about the Medical-Legal Partnership Project, please check the MLPP website at www.ccmckids.org/mlpp or, the CCA website at www.kidscounsel.org

MLPP is a joint medical-legal collaboration between the Center for Children's Advocacy, Connecticut Children's Medical Center, Charter Oak Health Center, Community Health Services, Inc., and Saint Francis Hospital and Medical Center. The project is funded through generous grants from the Hartford Foundation for Public Giving, the Universal Health Care Foundation of Connecticut, Connecticut Health Foundation, the Hartford Courant Foundation, and the Bob's Discount Furniture Foundation.

CASE SPOTLIGHT

**Preservation of Household Income:
The Case of Julia C.**

By Jay Sicklick, MLPP Director

Case Spotlight provides in depth analysis of a recent MLPP case and demonstrates how the collaborative intervention of pediatric providers and the MLPP results in the improvement of a family's health and well-being.

Background

Julia is a toddler who lives with her mother, an in-home family day care provider. On a recent well-care visit to her pediatrician, Julia's mother, Gloria, informed the clinician that she received a notice from the state Department of Public Health (DPH) that appeared to order her to cease providing in-home daycare, issuing a significant fine of over \$10,000 for providing "unlicensed day care" in her home. Gloria's sole source of income for her family (Julia, an older sister and herself) consisted of the money she earned providing home daycare services for various family members.

The Charter Oak Health center clinician immediately called for the assistance of an MLPP attorney to investigate the validity of the state's order. The pediatrician recognized the dire consequences that could result from a long-term loss of income, including risk of impending homelessness, and lack of adequate food and clothing for her pediatric patients. The MLPP attorney immediately conducted an intake and began to investigate the case.

MLPP Intervention

Upon investigation of Gloria's situation, the MLPP attorney determined that the in-home daycare consisted of babysitting services for family relatives. The MLPP student legal intern researched the public health regulations and determined that the relationships between Gloria and her daycare charges fell within the exception to the general rule that requires licenses for in-home daycare operations. The MLPP director sent a letter to DPH requesting a review and/or hearing based on the appropriate regulatory challenge. After several phone-conference negotiating sessions, the DPH regulators agreed to withdraw its notice and drop its demand for the hefty fine. Gloria immediately reopened her home to her relatives and recommenced her daycare provision.

For further information about this case or about the MLPP's legal intervention with our pediatric partners, please contact Jay Sicklick at (860) 570-5327, or e-mail jsicklic@kidscounsel.org.

Center for Children's Advocacy and Saint Francis Hospital & Medical Center Join Forces!

The Center for Children's Advocacy and Saint Francis Hospital and Medical Center (Saint Francis) recently concluded an agreement to provide MLPP services on site at Saint Francis to the departments of Pediatrics and Family Medicine, as well as to providers at the Burgdorf/Bank of America Health Center at Saint Francis' Mount Sinai Campus. In the coming months, the MLPP will establish its headquarters and a full-time office at the outpatient pediatrics center at

the hospital's Gengras ambulatory clinic at 1000 Asylum Street In Hartford. As with its other collaborative partners, the MLPP will provide on-site consultation services, accept patient/client pediatric referrals, provide education and training to pediatric and family medicine providers, and work with Saint Francis' clinical staff to provide systemic intervention and advocacy to address the legal and medical needs of children at risk. Saint Francis becomes the fourth medi-

cal institution in the Hartford area to welcome the MLPP, joining the Connecticut Children's Medical Center, Charter Oak Health Center, and Community Health Services.

For more information about the MLPP and its mission to improve the health outcome of children at risk through multidisciplinary intervention, call Jay Sicklick at (860) 570-5327, or email jsicklic@kidscounsel.org.