
Charlie Gard Life-Sustaining Care Act

Model Legislation & Policy Guide



*Advancing the Human Right to Life
in Culture, Law, and Policy*

INTRODUCTION

Over the last few decades, services that were once considered basic “humane care” have been redefined as “medical treatment.” Today, the American Medical Association (AMA), which defines “life-sustaining treatment” as including but not limited to “mechanical ventilation, renal dialysis, chemotherapy, antibiotics, and artificial nutrition and hydration,” argues that “[e]ven if the patient is not terminally ill or permanently unconscious, it is not unethical to discontinue all means of life-sustaining medical treatment in accordance with a proper substituted judgment or ***best interests analysis***” (emphasis added). In other words, the AMA endorses broad discretion for healthcare providers to withhold or withdraw life-sustaining care.

In addition, “futile care theory” is rapidly penetrating hospital care protocols. This theory provides that a healthcare provider or healthcare institution may unilaterally withhold medical treatment because the healthcare provider or healthcare institution believes that a patient’s quality of life is not worth continuing or it is simply not cost effective to do so, regardless of the wishes of the patient or the patient’s family.

The redefinition of “humane care” and the promulgation of “futile care” protocols place patients in peril. Conversely, patients benefit from state laws requiring unwilling healthcare providers or healthcare institutions to provide or continue life-sustaining care pending transfer to a willing healthcare provider or institution. In the wake of the tragic case of British infant Charlie Gard, it is essential that this standard be instituted in America before it is too late.¹

To assist states in protecting a patient from having life-sustaining care withdrawn or withheld against his or her will, Americans United for Life (AUL) has developed the *Life-Sustaining Care Act*.

For more information on AUL’s *Life-Sustaining Care Act*, or for drafting assistance, please contact AUL’s Legislative Team at Legislation@aul.org.

¹ Rachel del Guidice, *Pro-Life Leaders Rally to Support Charlie Gard*, The Daily Signal, (July 6, 2017) <http://dailysignal.com/2017/07/06/pro-life-leaders-rally-support-charlie-gard/> (last visited Oct. 6, 2022).

LIFE-SUSTAINING CARE ACT

HOUSE/SENATE BILL No. _____
By Representatives/Senators _____

Section 1. Title.

This Act may be known and cited as the “Charlie Gard Life-Sustaining Care Act.”

Section 2. Legislative Findings and Purposes.

- (a) The [Legislature] of the State of [Insert name of State] finds that:
- (1) Over the last few decades, services that were once considered basic “humane care” have been redefined as “medical treatment,” and may, therefore, be rejected by individuals in their advance planning documents or by their surrogates when they are incapacitated. For example, food and water supplied through a feeding tube has been redefined by some as “medical treatment,” with the term “artificial nutrition” coined to analogize the process to “medical treatment” rather than “humane care.”
 - (2) In some circumstances, life-sustaining care may be withheld or withdrawn at the discretion of healthcare providers or healthcare institutions.
 - (3) The American Medical Association (AMA), which defines “life-sustaining treatment” as including but not limited to “mechanical ventilation, renal dialysis, chemotherapy, antibiotics, and artificial nutrition and hydration” has stated that “[e]ven if the patient is not terminally ill or permanently unconscious, it is not unethical to discontinue all means of life-sustaining medical treatment in accordance with a proper substituted judgment or best interests analysis.”
 - (4) “Futile care theory” is rapidly penetrating hospital care protocols. This theory provides that a healthcare provider or healthcare institution may unilaterally withhold medical treatment because a healthcare provider or healthcare institution believes that a patient’s quality of life is not worth

continuing or it is simply not cost effective to do so, despite the wishes of the patient or patient's family.

- (5) "Futile care theory" contradicts "choice" and "patient autonomy;" instead, it is akin to euthanasia in that it replaces the ethic that all humans are equal and worthy of protection with one where doctors decide which lives are worth saving and sustaining.
- (6) Patients or their [*Insert appropriate term(s), e.g. "healthcare agent," "surrogate," or "proxy"*], whose desire that life-sustaining care be continued or provided is refused by a healthcare provider or institution benefits from state laws requiring the provision of life-sustaining care pending transfer to a willing provider or institution.
- (7) The law in the State of [*Insert name of State*] does not explicitly require healthcare providers or healthcare institutions to provide or continue to provide life-sustaining care pending transfer to a willing provider or institution.

(b) Based on the findings in subsection (a), the purpose of this Act is to require healthcare providers or healthcare institutions that decline to honor a patient or patient's [*Insert appropriate term(s), e.g. "healthcare agent," "surrogate," or "proxy"*]'s request for the provision or continuation of life-sustaining care to provide continuing life-sustaining care to the patient until a transfer can be effected and to make reasonable efforts to assist in the transfer of the patient to a willing healthcare provider or healthcare institution.

Section 3. Definitions.

As used in this Act only:

(a) **"Healthcare institution"** means any public or private organization, corporation, partnership, sole proprietorship, association, agency, network, joint venture, or other entity that is involved in providing healthcare services, including but not limited to hospitals, clinics, medical centers, ambulatory surgical centers, private physician's offices, nursing homes, or other institutions or locations wherein healthcare services are provided to any person.

(b) **"Healthcare provider"** means any individual who may be asked to participate in any way in a healthcare service, including, but not limited to a physician, physician

assistant, nurse, nurse aide, medical assistant, hospital employee, clinic employee, nursing home employee, or any other person who furnishes or assists in the furnishing of healthcare services.

(c) **“Life-sustaining care”** means health care including, but not limited to mechanical ventilation, renal dialysis, chemotherapy, antibiotics, and nutrition and hydration that, in reasonable medical judgment, has a significant possibility of sustaining the life of a patient.

Section 4. Duty to Provide Life-Sustaining Care.

(a) If a patient, a patient’s *[Insert appropriate term(s), e.g. “healthcare agent,” “surrogate,” or “proxy”]*, or a patient’s advance directive directs the provision or opposes the withdrawal of life-sustaining care that, in reasonable medical judgment, has a significant possibility of sustaining the life of a patient, a healthcare provider or healthcare institution shall ensure the provision *[or continuation]* of the directed life-sustaining care.

(b) A healthcare provider or healthcare institution that is unwilling to provide directed life-sustaining care under paragraph (a) may transfer the patient to another healthcare provider or healthcare institution capable of and willing to provide the directed life-sustaining care, but the unwilling provider or institution shall ensure the provision of the directed life-sustaining care until the patient is transferred. Any transfer of a patient under this subsection must be done promptly upon agreement by the receiving provider or institution to admit the patient.

Section 5. Right of Intervention.

The *[Legislature]*, by joint resolution, may appoint one or more of its members, who sponsored or cosponsored this Act in his or her official capacity, to intervene as a matter of right in any case in which the constitutionality of this Act or any portion thereof is challenged.

Section 6. Severability.

Any provision of this Act held to be invalid or unenforceable by its terms, or as applied to any person or circumstance, shall be construed so as to give it the maximum effect permitted by law, unless such holding shall be one of utter invalidity or unenforceability, in which event such provision shall be deemed severable herefrom and shall not affect the remainder hereof or the application of such provision to other persons not similarly situated or to other, dissimilar circumstances.

Section 7. Effective Date.

This Act takes effect on [*Insert date*].

For further information regarding this or other AUL policy guides, please contact:

AMERICANS UNITED FOR LIFE
1150 Connecticut Avenue NW, Suite 500
Washington, D.C. 20036
202.741.4917 | Legislation@aul.org

www.AUL.org

©2023 Americans United for Life

This policy guide may be copied and distributed freely as long as the content remains unchanged and Americans United for Life is referenced as the creator and owner of this content.