

BEFORE THE COUNCIL OF THE DISTRICT OF COLUMBIA COMMITTEE ON HEALTH AND HUMAN SERVICES

HEARING ON BILL 21-171, THE "HEALTH CARE DECISIONS ACT OF 2015" June 29, 2015

TESTIMONY OF WHITMAN-WALKER HEALTH

Whitman-Walker Health (WWH) is a community based, Federally Qualified Health Center dedicated to providing holistic health and wellness services to residents of the District of Columbia, and the entire Washington, DC metropolitan area, with a special focus persons living with HIV; lesbian, gay, bisexual and transgender (LGBT) individuals and families; and others in our diverse urban community who face health challenges. WWH is pleased to support the Health Care Decisions Act of 2015, with a modest suggested amendment to clarify that the MOST form can be used to meet the full range of medical needs that individuals may face when they are in crisis and cannot advocate for themselves.

For more than three decades, Whitman-Walker doctors, nurses, case managers, therapists and lawyers have worked with many thousands of persons living with HIV and other serious medical conditions. Many of these individuals have been alienated from family because of stigma, and too many have faced the end of their lives without adequate legal protections to ensure that their wishes were respected. Many of our older LGBT patients also are alienated from their families of origin and too many lost much of their support networks in the AIDS crisis of the 1980s and 1990s. Although our lawyers have helped many of these individuals to execute advance medical directives and living wills, a MOST document promises additional security that our patients and legal clients will be treated in a manner consistent with their needs and wishes in their last days or in other emergency situations when they may not be able to effectively advocate for themselves. A MOST document is a physician's order, and therefore more likely to be respected by other medical personnel in a

crisis situation than a living will. Moreover, a number of our patients, especially those of advancing age, do not have a family member or friend who can serve as a trusted representative to advocate for them in a medical crisis. A MOST order would provide additional security for those individuals.

We also support the MOST concept because it will encourage conversations between patients and their doctors about end-of-life situations. All too often, people avoid such discussions, and as a result too many individuals face medical crises towards the end of their lives without having provided sufficient guidance for their physicians, friends and families. In order to complete a MOST document, a physician will need to make sure she understands her patient's wishes, and this will be an incentive to have the conversation or conversations that may otherwise not take place.

In addition to their importance in directing the administration or withholding of CPR and other invasive interventions to prolong life, MOST orders could be particularly helpful for transgender persons by ensuring that they receive treatment that respects their gender identity.

Many transgender women and men are fearful of being mistreated or disrespected by EMT personnel and staff and physicians in hospitals, nursing homes and other facilities when they are particularly vulnerable. A MOST order which specifies the patient's gender identity and directs that they should be treated consistently with their identity – in dress, in use of their preferred name and gender pronouns, in room assignment, and in other respects – would provide a significant number of our clients, and other transgender persons, with a valuable sense of security. It will help to avoid the danger that a transgender person will encounter mistreatment that may be particularly devastating for them in a medical crisis or at the end of their life. A MOST order would also be important for many transgender persons who are on hormone treatment, to ensure continuation of that treatment during a period of time when they may be unable to advocate for themselves.

Although the statute's express purpose is to promote respect for the "patient's goals for care regarding the use of medical interventions . . . across health care settings," § 2(14), we are concerned that the language may be misunderstood to encompass only wishes regarding CPR and other life-prolonging interventions. Section 4(a) of the bill, which outlines the content of the MOST form, specifically identifies only "orders . . . regarding cardiopulmonary resuscitation and the level of medical intervention in the event of a medical emergency § 4(a)(1). The intent of the law is broader, and Whitman-Walker would be pleased to work with the Department of Health and the MOST Advisory Committee to develop the MOST form, but to avoid any misunderstanding of statutory intent we suggest that the bill be amended to make it clear that a MOST order can encompass all of a patient's goals for care in emergency situations. This could include not only treatment in accordance with gender identity for transgender persons, but also specification of medical conditions requiring special recognition, and a list of current medications and medications to avoid.

For example, Maryland's statute for Medical Orders for Life-Sustaining Treatment (MOLST) calls for the form to be

suitable for containing . . . written medical orders relating to a patient's medical condition, *including*:

- (i) The use of life-sustaining procedures;
- (ii) The use of medical tests;
- (iii) Transfer of the patient to a hospital from a nonhospital setting; and
- (iv) Any other matter considered appropriate by the Department to implement treatment preferences and orders regarding life-sustaining treatments across health care settings.

Md. Code Ann., Health-Gen. § 5-608.1(b)(2) (emphasis added). Similarly, West Virginia's Physician Orders for Scope of Treatment (POST) law is broadly worded:

The [POST] form . . . shall be designed to provide for information regarding the care of the patient, *including, but not limited to,* the following:

(1) The orders of a qualified physician regarding cardiopulmonary resuscitation, level of medical intervention in the event of a medical emergency, use of antibiotics and use of medically administered fluids and nutrition

W. Va. Code § 16-30-25(b) (emphasis added).

The Health Care Decisions Act of 2015 could be amended along similar lines, for instance by the following modest amendment to Section 4(a):

- (a) The MOST Form shall be designed to provide the following information regarding the patient's care and medical condition, including:
 - (1) The orders of an authorized health care professional regarding cardiopulmonary resuscitation and level of medical intervention in the event of a medical emergency, and any other matter considered appropriate to implement treatment preferences and orders regarding life-sustaining treatments across health care settings, in accordance with the choices, goals, and preferences of a patient or the patient's authorized representative;

Thank you for this opportunity to testify.

Respectfully submitted,

Daniel Bruner, Senior Director of Policy WHITMAN-WALKER HEALTH 1701 14th Street NW Washington, DC 20009 (202) 939-7628 dbruner@whitman-walker.org