

Meadowlark Hospice 709 Liberty Street Clay Center, Kansas 67432

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To: Kansas House Committee on Health and Human Services From: Amy Burr BSN RN CHPN, Director of Meadowlark Hospice

Date: 2/2/2024

Re: House Bill #2548

My name is Amy Burr and I am the director of Meadowlark Hospice. I have been serving as the director of our agency for eleven years. We are based out of Clay Center, KS and we serve Clay, Cloud, Republic, Washington, Marshall, and western Riley counties. I am also an active board member of the Kansas Homecare and Hospice Association and currently serve as a District 5 corepresentative. In January 2024, I started a 2 year commitment to serve on the National Hospice and Palliative Care Organization Quality and Standards committee. I would like to thank you for the opportunity to provide feedback on House Bill #2548 enacting the No Patient Left Alone Act.

While my agency is not directly affected by the implementation of the provisions of the bill, the patients we serve will be affected. Our agency serves the rural community and 55% of the patients we care for reside in a facility. During the Covid pandemic, we encountered many scenarios of patients dying without their loved ones. We routinely had to work through the regulations and navigate the loopholes that facilities were finding to restrict visits for end of life residents. I feel very strongly that it is important to have provisions in place to prevent this inhumanity from occurring again.

I am providing this written testimony today to support that the overall goal of the bill is good, but I have concerns with some of the provisions outlined. My concerns lie with page 2 lines 38-43. I feel the provisions allow for a loophole for facilities to continue the restriction of visits for the patients outlined in lines 19-29 also on page 2. Here are my statements regarding those provisions.

Line 39 and 40: Adopt visitation policies and procedures that are more stringent for intensive or critical care units. The concern I have is for the patients this is written to protect. They are the ones that need to have less stringent visitation when in this care setting. Excluding loved ones during these critical times are a disgrace to the patient and the loved ones. Presence is what helps loved ones understand what is going on and helps them make better informed decisions. The patients outlined in this bill are those that need someone to make medical decisions for them and by eliminating the loved ones or decision maker from the bedside, you are taking away the opportunity to make a well informed decision. Decisions that are made in this manner lead to coping difficulties for the loved ones as well as the patient. I feel other provisions of the bill allow for when the visits are disruptive and the facility needs to create some space for the patient.

Line 41: Modify visitation based on a patient's condition or need for rest. This modification when you are thinking of end of life could easily allow for the restriction of visitors. Patients will naturally decline and need more rest due to their disease process, but those are the instances we are wanting to allow loved ones to be by their side. I can see and have witnessed a facility make a modification on a



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whim. It would be easy for a facility to say if the patient is resting peacefully, they will not allow visitors. By writing this as a provision in this bill, the facilities are given power to make the decision on the need for rest or if they feel the patient's condition is worthy of visitors or not. In a long term care facility, this would be an easy loophole to be able to exclude visitors for a resident.

Line 42 and 43: Requires a visitor to agree in writing to follow the facility's policies and procedures. It provides a loophole to give the facility the opportunity to have only certain designees available to delegate the written agreement. This could easily exclude visitors outside of normal hours because the designee isn't present. The act of having this required in writing creates an opportunity for a facility implemented process that could intentionally limit visitation. A simple posting of the expectations should be suitable and available to refer back to if the visitor becomes disruptive.

The provisions outlined above each provide opportunity for loopholes to impede the intent of the bill proposed. I feel that by excluding the first two provisions and amending the third, we can better ensure that this bill will be able to serve its intended purpose. As I stated earlier, I believe this bill is overall good and necessary to protect the human rights of the people of Kansas. Every person should be able to be comforted by loved ones in their hardest and/or final moments, if that is their desire. The decision to have presence of others in your final days should not be left to the decision makers of where you reside. We can certainly do better than we did during the Covid pandemic in ensuring patient rights. Thank you for your consideration on this bill and my concerns on the provisions outlined.

Sincerely,

Amy Burr BSN RN CHPN

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