

Dear Chair Gelser and Senators,

Thank you for this opportunity to talk with you today. I am Wendy Sinclair. I represent a group of Oregonians with serious painful medical conditions. Some of which receive palliative care and others who would greatly benefit from it, if only their practitioners had a clear definition of palliative care.

I want to talk specifically about the modification offered by the Palliative Care Council on bill SB 179. I am hoping SB 179 will serve as a consolidated definition of palliative care. My hope is that it will encompass the sect of the population that is currently excluded due to a lack of clarity on how palliative care is defined.

With the introduction of SB 608 in 2015, I had hoped there would be consistency in palliative care for those with serious illness. I had hoped that 608's definition would have been adopted by the Oregon Health Authority, Associations, and Councils who support and educate doctors and their patients on palliative care. Unfortunately, that has not happened. When I asked the Palliative Care Council coordinator for a definition of palliative care he was unable to give me one. This shows the confusion that is still present even in groups responsible for guidance and clarification.

I ask that the definition adopted in this bill be given to the Oregon Health Authority and other organizations as the official palliative care definition with instructions to adopt it. This would help in fair and equal access of care for those on Medicaid.

I appreciate both the CMS and the National Center for the Advancement of Palliative Care's definitions which have been presented for inclusion in this bill. Both of which are consistent with SB 608.

Currently, many patients who could qualify for palliative care are not given that opportunity, and unless they are educated and advocate for themselves, their doctors don't consider it.

Many doctors believe a patient has to be at the end of their life with only 12 or 6 months to live to qualify for palliative care. This comes from the very confusion I'm concerned will continue unless the definition is solidified. Some interchange palliative care with the qualification for hospice care. When this is misunderstood it essentially voids palliative care altogether because the only access to a higher level of care then

becomes hospice. This is why the difference between hospice and palliative care needs to be emphasized. If palliative care is more than hospice care, this needs to be clarified.

I hope that all references to end of life, or twelve months to live, or six months to live, life threatening, or conditions with a high risk of mortality will be eliminated from the original bill and the proposed amendments by the Palliative Council. If not, patients who desperately need these services, and practitioners who could provide them, will continue to misunderstand palliative care as hospice care.

An issue of additional concern is that pain care is an integral piece of palliative care, however seriously ill patients are losing pain care. Most prescribing policies for analgesics allow exemptions for cancer, hospice and palliative care. However, without clearly defined palliative care, seriously ill patients in high levels of pain are losing their opioid pain medication. Practitioners need access to a clear definition when exemptions to pain or other policies are involved.

I am also concerned with the requirement that, “patient and family agree to participate in advanced care planning discussions.” It reads as if the family’s consent to participate is required, does that exclude those who don’t have family, or whose family doesn’t agree with the care? This is a reality for some seriously ill patients. This could also encompass those with family members who refuse medical treatment (altogether) for themselves based on their beliefs, but then would this be imposed on the potential palliative care patient regardless of their health needs, or individual beliefs? I see reference to preserving patient’s autonomy, which I feel is vital, but does the addition of this requirement negate that?

Thank you for hearing my concerns. I am hopeful this Bill will clarify palliative care. I hope this will provide a clear and extensive definition that will be inclusive of those who need a higher level of care, and who can benefit from the protections it provides.

I’m providing my email, please feel free to contact me with any questions.

Sincerely,

Wendy Sinclair

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For reference (I'm sure you have these, but for quick reference).

Council's proposed edits:

<https://www.oregon.gov/oha/HPA/DSI/Palliative%20Care/PCAC-Materials-2.7.2019.pdf>

Source of the definition proposed by the Council:

<https://www.capc.org/about/palliative-care/>

<https://www.capc.org/topics/palliative-care-guidelines-quality-standards/>

https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf

Senate Bill 608

<https://olis.leg.state.or.us/liz/2015R1/Downloads/MeasureDocument/SB608/Enrolled>