

Dear Senators

Thank you for the opportunity to speak with you today. Hopefully, I can keep it brief. I'd like to give an outline of who I am, what I suffer from, and why I'm here. To start off with, I am a 55 year old woman with a progressive, debilitating, intractable spinal cord disease called adhesive arachnoiditis (AA). Arachnoiditis is inflammation of the arachnoid which is the middle layer of the spinal canal covering, the outside layer being the dura and the inside, the pia mater. This covering is like a "pipe" that encompasses the spinal cord, nerve roots known as the "cauda equina", and fluid that flows up and down inside the canal. ~~Arachnoiditis is when the arachnoid becomes inflamed.~~ Common ^{causes} reasons are trauma, viral, chemical (injections), and degenerative changes. If not treated in the inflammatory stage, arachnoiditis can go on to the next stage where the nerve roots adhere to the arachnoid layer. There are four stages of arachnoiditis; mild, moderate, severe, and catastrophic. When arachnoiditis reaches the adhesive stage, it's considered "adhesive arachnoiditis". Unfortunately, AA may cause severe neurologic damage and severe pain as it may become a progressive, neuroinflammatory disease whose pain has been compared to stage four cancer. I'm in the catastrophic stage of the disease.

Although AA is considered a rare disease, its numbers are on the rise both due to invasive treatments, chronic spinal conditions, and an educational campaign to inform both the public and medical providers of its existence. The bad news is that it often takes years to obtain a proper diagnosis, and many find themselves in the late stages of the disease by the time they are diagnosed with AA.

As with any other serious or chronic illness, AA needs to be treated as a serious complex disease, not unlike MS. Emergency room visits and medical costs associated with it can be lowered by coordinating the care to alleviate symptoms, reduce pain, and using curative measures. My treatment protocol involves an anti-inflammatory diet, specialized

aquatherapy, multiple vitamins and minerals to balance the deficiencies that come with a chronic disease, hormone replacement therapy, anti-inflammatories, muscle relaxers, sleep aides, pain medication, and prescription medications, and they are all just as important as the other.

This brings me to why I'm testifying. As I'm sure you're aware, many patients with serious illnesses are being medically abandoned due to the opioid overdose crisis. These are patients who've been on stable doses of pain medication, submitted to urine testing, signed pain contracts, and have well documented illnesses yet many are suffering as we speak. Many are left to fend for themselves and their untreated pain. This winds up causing life threatening endocrine imbalances and increased risk of heart attack and strokes from elevated blood pressure, not too mention feelings of suicide to escape the pain.

Over the past couple of years, I have heard from many of my fellow AA sufferers (and those with other diseases) that they've been forced tapered off their effective and stable doses of pain medication. They talk about being released from pain management, while Intense scrutiny by state and federal law enforcement entities is causing many pain specialist to either leave the profession or turn to dangerous invasive procedures, and primary care doctors to stop prescribing altogether. Many of us have very serious comorbid conditions, and finding doctors that are trained to treat complex serious illnesses is not easy and often involves traveling long distances. This is where I feel that palliative care could be an option. Personally, I've spent almost two years trying to get a team of doctors I need to manage my disease, and am still having problems finding a neurologist to treat my AA. It would be so much easier for my care to be coordinated and managed through palliative care.

In 2015, Oregon enacted SB 608 which in section 5 defines palliative care as, "Serious illness" means any illness, physical injury or condition that

substantially impairs a patient's quality of life for more than a short period of time". In my opinion, most intractable pain patients fit this definition. It does not say life-threatening, end of life, or cancer and I've spoken with many patients and doctors who are under the impression that this is the case and who are not aware of SB 608. The Oregon Health Authority (OHA) is tasked with messaging SB 608, but are failing dismally. It's very difficult, almost impossible to find any reference of this bill and wording contained in it on OHA's website. Reading through the material's from the Palliative Care and Quality of Life Interdisciplinary Advisory Council, I ran across the different definitions of palliative care. In the memo on SB 177, it states under the summary that palliative care is suppose to use the current national Center for Advancement of Palliative Care guidelines (CAPC) which states palliative care is defined as a serious illness that "carries a high risk of mortality and either negatively impacts a person's daily function or quality of life or excessively strains their caregiver." In the same document on the next page of the memo on SB 177 under current issue you see the wording "unlike hospice, palliative care patients are not required to have a life limiting prognosis and can continue to receive curative medical treatments and interventions." As you can see, they contradict each other. The lack of consistency for the definition is confusing to say the least and I'm hoping that you can clear this up for me.

Thank you,

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Senate Bill 608

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

PCAC materials

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

See page 65 for palliative care definition

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

Arachnoiditis

Handbook<http://foresttenant.com/foresttenant/wp-content/uploads/2018/06/AA-Basic-Handbook.pdf?v=June2018>