

## **Written evidence submitted by Ann Jackson (ADY0276)**

My name is Ann Jackson. I have been a resident of Oregon all my life. I recently moved from Portland south to Wilsonville. I have worked in the field of end-of-life care for nearly 36 years, the first 20 as CEO of the Oregon Hospice and Palliative Care Association. From 1988 to 2008, I was its representative for all responsibilities related to Oregon's Death with Dignity Act (ODDA) before, during, and after it became law.

The Oregon Hospice and Palliative Care Association (OHPCA) is neutral on assisted dying and its policy statement can be read here: <https://oregonhospice.org/hospice-and-dwd/>. The OHPCA is a state-wide public benefit organization committed to improving the quality of life for Oregonians at the end of life and supporting the hospice and palliative care organizations that provide care.

I am now an independent and unaffiliated consultant often asked to comment about the ODDA. A link to an updated copy of my CV/Bio is on the home page at [www.ann-jackson.com](http://www.ann-jackson.com).

I am writing now to address issues that you will be considering as you debate voluntary assisted dying in the United Kingdom.

### **Palliative care and assisted dying**

I voted against the ODDA twice, in 1993 and in 1997. I strongly believed that assisted dying was unnecessary if Oregonians had access to high quality hospice and palliative care. By the time the Act was implemented, all Oregonians did have access. But after its implementation, I soon recognized how arrogantly dismissive I had been. There are valid needs that hospice and palliative care professionals cannot meet effectively. *Palliative sedation*, for instance, is not an acceptable option for most persons who value autonomy.

That said, I support hospice *and* voluntary assisted dying. They complement each other very well.

In fact, between 1997 and 2021, more than 90% of persons who used the ODDA were enrolled in hospice. In 2021 98% of those who hastened their dying under provisions of the law were also hospice patients. This is evidence that they did not end their lives because symptoms were not addressed. In the USA, hospice is recognized as the gold standard of palliative care. Hospice is a legally defined benefit offered to persons who have an estimated life expectancy of 6 months or less and provides care at home and across all other settings.

Some persons with a life expectancy of fewer than 6 months, such as those continuing curative treatment, may prefer palliative care over the full array of hospice services. No person who is dying should ever have to choose the ODDA as an alternative to hospice and/or palliative care. Nor should they have to choose palliative care or hospice as an alternative to the ODDA, if they are eligible.

Nearly all persons who used the ODDA had health insurance. However, Oregon's health plan covers the cost of hospice for persons who do not have the ability to pay. All health plans offer palliative care as well.

### **Slippery slope arguments are fallacious**

The Oregon Death with Dignity Act (ODDA) became law in 1997, the first jurisdiction in the world to make PAS or assisted dying a legal option. The Oregon Health Authority (OHA) issued its first annual report in 1999 and issued its 24<sup>th</sup> annual report on March 15, 2022. Each report is a wealth of data. As a compendium, they reflect the stability of the Act. Oregon must not ignore this information: We must learn from the science—and offer what we have learned to other jurisdictions.

There have been no abuses of Oregon's law. Those who drafted the ODDA were very, very conservative, as were those who wrote the regulations that administer it in practice. I was among them. Our primary aim was to ensure that the Act would result in no harm to the persons who used it. Nor to physicians and other health care professionals supporting the persons who used it.

Fact- and experienced-based research published in highly regarded journals support the successful implementation of Oregon's law. Oregon has very responsibly been closing the data void about assisted dying as it is practiced in a legal environment.

Deaths under the ODDA are not recorded or understood as suicide. There is a wealth of expert commentary on the differences between suicide and the wish of a dying, competent individual to control the manner and timing of their death through assisted dying.

It is important to note, contrary to the "noise", that there have been no abuses within the provisions of the ODDA. Nor has the ODDA changed other laws or values in relation to suicide. Those persons who assist in a suicide are subject to charges of manslaughter or murder in the State of Oregon.

All laws must be reviewed and examined over time and amended or repealed, as the science dictates. There were only minor house-keeping changes made to the ODDA until 2019. It was amended then, to allow a person who has a prognosis measured in days, not months, but meets all other requirements of the ODDA, to ingest medication without the required waiting periods. The legislature agreed that to deny access in these circumstances is cruel.

And in 2022, as a settlement to a lawsuit challenging its constitutionality, Oregon residency was removed as a requirement to access the ODDA.

Amendments or tweaks that have been proposed suggest that the Act, as initially passed, is too conservative and not reflecting current needs or times. It is important to note that *the fundamental eligibility criteria of the ODDA: being mentally competent and terminally ill with a prognosis of six months or less, have not changed* in the 25 years since the law came into effect.

The USA now has 41 years of experience and 10 states and the District of Columbia where citizens may hasten their deaths.

Arguments that amending the ODDA are steps down a slippery slope are fallacious. When science dictates reconsideration, actions should be taken. *"Slippery slopes" are irrelevant red herrings.*

### **Prognoses are overestimated**

In 2015, Oregon's Legislature rejected a bill that would expand the life expectancy criteria to one year from 6 months. The question was whether a safeguard in 1997 was proving a burdensome barrier in

2015. Science suggests and research supports that 70% of physicians overestimate life expectancy—significantly more often than underestimate.

However, the Legislature and the end-of-life community agreed that consistency with the federal Medicare/Medicaid Hospice Benefit and its requirement of a six-months prognosis was an important consideration. I was a member of the federal task force that developed disease-specific guidelines for determining prognoses. Those guidelines should be an invaluable tool for physicians and assurance that persons qualify for the ODDA. However, the median length of stay in hospice in the USA remains only 20 days, far under 6 months.

Overestimating life expectancy denies patients timely admissions to hospice services, an entitlement under Medicare, and denies persons their right to use the ODDA.

In 2021, the median time between the first request for a prescription and a patient's death was only 30 days, far less than six months. Furthermore, this includes an outlier of 1 person of 238 persons who had made the request 1,095 days before death.

I see no evidence that persons hurry to use the ODDA because they have been given a six-months prognosis. In my experience, people do not want to die. They prefer to live. They are comforted when they have a prescription, and they get on with living. They use the prescription when dying—and suffering—become too burdensome. About one-third of those who go through the process and receive a prescription under the ODDA never use it. This points to the peace of mind that having a choice brings to many dying people.

### **Being a burden is a specious argument**

I am a co-investigator of published research that overwhelmingly determined that *all persons who are dying worry that they are a burden* to their family and loved ones. Not just those who use the ODDA.

### **“Growth” in number of cases**

The ODDA has been used infrequently, although a graph of cases between 1998 and 2021 suggests a steep climb. In 1998, 6 of 10,000 persons who died ingested medication under provisions of the ODDA. In 2021, the number was 59 of 10,000, fewer than in 2020. From less than .01 percent to less than 1 percent over 24 years.

### **Disabled persons are not coerced to use ODDA**

*“Disability Rights Oregon* has never received a complaint that a person with disabilities was coerced to make use of the [Oregon Death with] Dignity Act”. Bob Joondeph, its executive director, confirmed that this statement, first made in 2007, remained true in 2020.

It is important to note that, in 2021, 98% of all persons who used the ODDA were enrolled in hospice. Hospice personnel include doctors, nurses, social workers, physical therapists, aides, and volunteers, all of whom visit patients in their homes. Hospice workers are in a unique position to monitor patient and family well-being.

## **Mental Health Evaluations**

Referrals to psychiatrists/psychologists are very infrequent, although they are required if a prescribing physician questions a person's capacity to make health decisions. The referrals are infrequent because the bar is high enough that persons who lack capacity are rarely able to carry out requirements for eligibility.

## **Death Certificates**

That a person uses the ODDA is not relevant to agencies that are routinely provided a death certificate, such as a mortgage carrier. Death certificates in Oregon are not public records. There are superior methods for collecting data. In Oregon, the state is informed when a prescription is written.

## **Informing Patient Families**

Family members are never entitled to health care information, under federal law. A recommendation by their doctor that they do inform family is appropriate—as are reasons why.

## **Implications for Doctors**

Doctors who accept a request from a patient to write a prescription understand their responsibilities. No doctor should be required to accede to a request. I do believe, however, that doctors and medical centers should be more open and honest about policies that would allow or restrict participation. And to be more open to conversations about options at the end of life.

It is important to note that, unless a patient's doctor is willing to write a prescription—or even to make a referral, the patient is unlikely to know the doctor who will. However, these are relationships that develop rapidly. I can attest to that statement.

## **Closing with a personal qualification**

My life partner died of cancer on December 3, 2019. He was one of 188 persons to use the ODDA that year. William Cary Duncan III, M.D., vascular surgeon, born in Ware, Massachusetts, who morphed into a cowboy in Oregon. In October, Bill made his three required requests for a prescription, and was also admitted to hospice. He was very anxious to have the medication and adamant about using it immediately. It was to arrive on Saturday, and on Friday, at his request, I arranged to have a volunteer from End-of-Life Choices Oregon (EOLCOR) with us. EOLCOR is a not-for-profit charitable organization that provides support to persons considering a prescription.

Immediately after I informed Bill that Peter, his good friend, and medical director of EOLCOR would be arriving at 4 p.m. on Saturday, the telephone rang. My daughter and her husband invited Bill to join them on Sunday to watch the Boston Patriots game. "Well, that's an invitation I can't turn down!" Bill exclaimed.

His medication was set aside—and as for so many others who have used the ODDA, he got on with living, comforted by its proximity. On Friday, November 29, the day after Thanksgiving, Bill and his daughter, my daughter and I, and our old Afghan Hound were finally able to drive across the Santiam Pass over the Cascade Mountains. Bill had a home on an old ranch in Central Oregon. The roads were rough and icy, very hard on his exhausted and emaciating body. Blizzards and “bomb cyclones” had delayed our crossing for several weeks. While a bundled-up Bill waited in the heated car, we shoveled snow and cleared a path for his wheelchair. Then we all settled in for a few days, cozy before the wood stove, and sleeping under down comforters.

Thus, Bill, who had always lived large and did not want to die, chose to end his dying on a quiet, snowy day in his own bed at his beloved log cabin in Camp Sherman, Oregon. I was with him, as were Lisa and Meg (his daughter and mine), and a volunteer from EOLCOR. Bill was resolute when he drank his medication. His chaser was an Old Fashioned—our favorite cocktail at the Savoy. He barely sipped it before he was sound asleep—and so very peaceful.

I remain bereft.

Thank you. Please let me know if you have questions—or if I can elaborate in some way.

*Jan 2023*