From:

To: <u>Joint Select Committee on End of Life Choices</u>

Cc:

Subject: Submission assessing practices related to Oregon"s Death with Dignity Act

Date: Wednesday, 25 April 2018 4:44:27 AM

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Letter to Guernsey Press about Oregon aid in dying claims.pdf

Ann Jackson, M.B.A.

APRIL 24, 2018

Joint Select Committee on End of Life Choices <a href="mailto:eolcc@parliament.wa.gov.au>

Dear Committee Members,

My name is Ann Jackson. In June 2008, after 20 years, I retired as Executive Director and Chief Executive Officer of the Oregon Hospice Association (OHA), during which time I was involved in the public debates around assisted dying. I remain involved now, ten years later, as an independent and unaffiliated consultant about end-of-life options.

It is my understanding that in the Parliament of Western Australia is currently conducting an Inquiry into End of Life Choices and that Oregon's assisted dying law has become a matter of discussion.

A letter to the Guernsey Press published on 17 April 2018 came to the attention of Mr Ian Wood, who has asked that I send a copy to the Joint Select Committee. https://guernseypress.com/news/voices/readers-letters/2018/04/17/i-am-convinced-that-physician-assisted-dying-can-be-and-is-practised-responsibly/#Yu3iID6I6oxGZ4v7.99

It is important to note that I write to you in my personal capacity and I have no intention of interfering in the debate to legislate for voluntary euthanasia or assisted dying in Western Australia. I am concerned, however, that the situation in Oregon is represented fairly.

I hope the attached letter will help clarify the Oregon law and its claimed consequences based upon my professional experiences. I am happy for you to contact me and to share the letter with your colleagues in Parliament if you feel it

may be of benefit.

Yours sincerely,

Ann Jackson, M.B.A.

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It is important to note that I write to you in my personal capacity and I have no intention of interfering in the debate to legislate for voluntary euthanasia or assisted dying in Western Australia. I am concerned, however, that the situation in Oregon may be misrepresented.

I hope the attached letter will help clarify the Oregon law and its claimed consequences based upon my professional experiences. I am happy for you to share this letter with your colleagues in Parliament if you feel it may be of benefit.

Yours sincerely,

Ann Jackson, MBA

ANN JACKSON, M.B.A.

April 15th 2018

Dear Sir,

My name is Ann Jackson. In June 2008, after 20 years, I retired as Executive Director and Chief Executive Officer of the Oregon Hospice Association (OHA), during which time I was involved in the public debates around assisted dying. I remain involved now, as an independent consultant about end-of-life options.

It is my understanding that Oregon's assisted dying law has become a matter of debate in Guernsey ahead of a vote in May on whether to legislate for assisted dying on your island. When I was made aware of a recent letter published in the Guernsey Press (9 April) entitled 'Oregon assisted-suicide model too good to be true' I felt compelled to offer my professional experiences and put right misleading claims made by the author, Tony Meadowcroft. I hope that this letter also addresses concerns of Catherine Hall (Guernsey Press 13 April).

There are various reasons people may oppose assisted dying but I do believe that the debate, wherever it occurs, should be based on evidence and facts.

As Chief Executive of the OHA, I acted as its primary spokesperson on physician-assisted dying before and after the Oregon Death with Dignity Act (ODDA) was implemented. The ODDA was introduced as a voter initiative (referendum) in Oregon—I voted in opposition to the Act. I have subsequently changed my mind and fully support the Act. The OHA has also subsequently dropped its opposition.

Today I am convinced that physician-assisted dying can be, and is, practiced responsibly in Oregon, and that the ODDA is a very well-crafted law. I feel it is important to correct some of the misrepresentations made about the consequences of assisted dying in Oregon:

1. There has been a profound shift in attitudes towards terminally ill patients in Oregon

I will concede on just one of Mr Meadowcroft's points. There has indeed been profound change, but for the better. The ODDA has facilitated discussion of important issues, allowing more open and honest conversations between dying patients and their physicians and more careful evaluation of all end-of-life options. These discussions more often lead to reassurance of the dying patient than an eventual direct request for life-ending medication.

2. The safeguards built into Oregon's physician-assisted dying law are followed to the letter

The law has remained unchanged over the past 20 years and is only available to dying people of sound mind —these criteria, and the safeguards associated with them, have not broadened since the law was enacted. Fears of a "slippery slope" have not come to fruition and there are no proven cases of coercion of individuals to have an assisted death. The risks of patients being murdered or coerced into ingesting life-ending medication were far greater prior to the implementation of a transparent system with upfront safeguards and effective regulation.

3. The overwhelming majority of terminally ill patients who ingest life-ending medication at a time and place of their choosing die peacefully, without complications

More context must be given to Mr Meadowcroft's broad statement that there are complications with physician-assisted dying. There have been no reported complications in over 98% of cases of people dying under the ODDA. For others, complications are associated with symptoms that are commonplace among people at the very end of life, such as regurgitation. Furthermore, we cannot ignore the significant likelihood that many people who have made use of the ODDA would have experienced very distressing symptoms and complications if they had no choice but to endure their suffering.

4. There is rigorous monitoring and data is made available publicly every year

Physician-assisted dying is monitored and controlled by stringent criteria and processes, mandatory state reporting by the medical team, and medical board oversight. The justice department also has the power to investigate should concerns ever arise. Assisting a suicide outside the provisions of the ODDA is an unlawful act and subject to criminal penalties.

5. The Oregon Medical Association is neutral on the issue of physician-assisted dying

Mr Meadowcroft's assertion about the Oregon Medical Association is false. The Oregon Nurses Association is also neutral, and both organizations support their members to participate in assisted dying in line with their individual values. The Oregon Hospice and Palliative Care Association (formerly OHA) supports the rights of terminally ill Oregonians to choose any and all legal end of life options, as does the American Public Health Association. As of 2017, 57% of US physicians say they believe medical aid-in-dying should be available to terminally ill people.

6. Hospice and palliative care in Oregon is consistently rated among the best in the USA, and assisted dying has not had a negative impact

Oregon is within the top quartile of overall hospice use across the US. I have met with front-line hospice workers regularly over the years to discuss their experiences and whether they supported or opposed physician-assisted dying or the ODDA, there was unanimous agreement that conversations about death and dying improved significantly

Ninety percent of those who use the ODDA are enrolled in hospice, which is the gold standard for pain and symptom management. OHA recommended immediately on passage of the ODDA, that persons considering a request for a prescription be referred to hospice. Oregon's hospices were adamant that people not choose assisted dying because they were in pain. No hospice in Oregon denies a patient access to their care because they intend to use the ODDA. No hospice in Oregon will turn away a dying patient because they cannot afford to pay. There is no excuse in Oregon for anyone to die in pain and suffering.

7. Terminally ill patients requesting physician-assisted dying do so for multiple and complex reasons

Through my experience of Oregon's law, I came to realize that it was cavalier of me to believe that hospice and palliative care professionals could indeed meet all the needs of people who were dying, or that some needs were less worthy than others, such as the need to manage the circumstances of one's death. It is true that the vast majority of people who have an assisted death in Oregon cite the loss of their autonomy, and/or being less able to engage in activities making life enjoyable. But suffering is a deeply personal and subjective phenomenon.

Mr Meadowcroft suggests that unless suffering has a physical basis it is somehow unworthy. This is not an accepted viewpoint for anyone who has experience with people who are dealing with a terminal illness.

Fewer persons cite inadequate pain control or concern about future pain as a reason for wanting a prescription. Ninety percent are enrolled in hospice. Their pain and other symptoms *should* be managed.

Palliative sedation is an effective way to ease suffering of those whose symptoms cannot be brought under control. However, being sedated to a point of coma is not an acceptable option for most persons whose primary concerns are about losing autonomy, their quality of life, and dignity—as they define dignity.

If patients are not experiencing actual untreatable pain, Mr Meadowcroft suggests that many cases of assisted dying are motivated by a desire not to become a burden. Being a burden is another reason given for using the ODDA. But no one in Oregon can have a prescription simply because they do not want to be a burden. Research confirms that such concerns are held by most dying people, regardless of whether they use, or do not use, assisted dying.

Financial implications of treatment are the least important reasons given for using a prescription under provisions of the ODDA. Nearly all persons who have used the Law have had medical insurance. Hospice is a covered service of private health plans and Medicare. Some private health plans cover the ODDA. The Oregon Health Plan, Oregon's Medicaid program for those who lack financial resources, covers treatment for life-threatening illnesses, hospice, and the ODDA. The Oregon Health Plan, however, does not cover drugs or treatments that are considered 'futile', or to have less than a 5 percent chance of a 5-year survival. This should allay Ms Hall's concern.

8. Mr Meadowcroft's claim that some patients who receive a prescription for life-ending medication outlive their prognosis misses the point

Over a third of the terminally ill people who are eventually granted a prescription for life-ending medication do not use it – for many, it is simply 'emotional insurance'. This reassurance and peace of mind can result in a general improvement in their wellbeing, meaning some go on to outlive their original prognosis. Some may die during the waiting period, perhaps having been given too much time.

In the majority of cases a predicted life expectancy of six months or less is reasonable, but ultimately Oregon's law is for dying people to retain complete control over decisions they make about their deaths. To clarify, dying people who want this choice

for themselves do not want to die, they want to exercise control over an imminent and inevitable death. Using the ODDA is always a last resort.

Therefore the idea that someone outliving their prognosis is a bad thing or suggests the law isn't working is, frankly, missing the point.

I hope this letter is helpful in giving a more accurate picture of what really happens in Oregon. I know that your goal is to inform your readers. Mine is to offer open and honest information based on data and facts. Good end-of-life decision making requires good information.

Yours sincerely,

Ann Jackson, M.B.A.