

MAKING JUSTICE WORK IN WALES: A RESPONSE FROM MY DEATH, MY DECISION.

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About us

My Death, My Decision is a grassroots non-profit organisation that campaigns for the legalisation of assisted dying in England and Wales. As a growing movement we are at the forefront of social change: nearly 90% of the public now favours a change in the law to allow adults of sound mind, who are either terminally ill or facing incurable suffering, the option of a peaceful, painless, and dignified death.

My Death, My Decision believes that legalised assisted dying should not be restricted to only those with six or fewer months left to live. We believe that just as compassion for others has motivated people to support assisted dying for those who are terminally ill, it should also underscore support for those facing intolerable and incurable suffering, as faced by our patron Paul Lamb. Through the work of our members, supporters, patrons, and activists we help to broaden the public debate on assisted dying and seek to secure changes in the law.

Our Methodology

Within this consultation response My Death, My Decision comments on the seemingly disproportionate impact the current law prohibiting assisted dying may have upon Wales. There are two preliminary points which should be made about these comments. Firstly, it is important to note that our figures are likely to be conservative as they are based on statistics released to us on the number of people who travelled from the UK to the Swiss organisation Dignitas. Accordingly, our figures do not include the number of citizens who travel to alternative organisations such as Lifecircle, EX International, or Pegasos. In view of this, it is also therefore important to recognise that our comments are provisional, as we recognise further investigation may be necessary.

Our Recommendation

We are pleased to respond to the Senedd's important consultation and share our recommendation in support of allowing Wales to determine its own law on legal, safe, and compassionate assisted dying.

We support the view of Lord Thomas of Cwmgiedd and the Commission on Justice in Wales and believe that powers to control justice and policing should be devolved to the Senedd. A particularly compelling reason to do so would be to enable the Senedd to address one of the most pressing injustices currently affecting Wales: the prohibition of assisted dying.

There is now compelling evidence to support a change in the law which would allow adults of sound mind, who are either terminally ill or facing incurable suffering, the option of an assisted death; subject to robust safeguards. Yet, even if Wales decided not to reform the law, it is our view that the authority to make such a choice should be vested within the Senedd. Therefore, as an area of concern, we recommend that the Senedd should request for this specific issue to fall within its devolved competencies.

Our recommendation is based on three factors.

1) The Senedd's inability to determine the legality of assisted dying puts it at odds with other devolved administrations across the United Kingdom.

¹ 'New research finds up to 93% of people consider assisted dying acceptable in at least some situations, even if rarely.', National Centre for Social Research (2019). Accessible at: <https://www.mydeath-mydecision.org.uk/wp-content/uploads/2019/03/Briefing-on-NatCen-assisted-dying-poll.pdf>

As a matter of general principle, it is the view of My Death, My Decision that the legitimacy of the Senedd is, or at the very least should be seen to be, equal to that of other devolved administrations across the United Kingdom and Crown dependencies. This is the case for two reasons. Firstly, following the devolution of additional law making competencies, most notably in Health and Social Care, the Senedd's role is now arguably equivalent to that of other Parliaments across the United Kingdom; a point symbolically recognised in May 2020 when the Senedd transitioned from an Assembly into a Parliament. Secondly, we recognise that popular support has now grown in Wales for a separate legislative jurisdiction, as demonstrated by 63.49% of the electorate voting 'yes' in Wales' 2011 Devolution Referendum; and accordingly we believe it must therefore be correct, as a matter of principle, that the Senedd should have comparable competencies to other Parliaments across the United Kingdom, such as in the fields of law and justice.

Beyond this general observation, we believe that there is also a specific devolutionary case in support of assisted dying. It is now well established that certain morally subjective issues fall within the margin of appreciation for devolved administrations. For example, this category of issues include the regulation of abortion and organ donation. Another issue which fits squarely within this category is the legalisation of assisted dying. Hence, different administrations have historically always had the power to determine their own law on this matter; except in the case of Wales.² Given the Senedd's comparable status as a legislative Parliament, we believe that a consistent application of this principle would also entitle the Senedd to also determine its law on assisted dying.

Setting aside the fundamental inequity of this arrangement, we believe there are two further principled reasons why the present situation is unacceptable.

Firstly, there is a notable difference between the views of the public in Wales and the rest of the UK on assisted dying. Although assisted dying reform, for both those who are terminally ill or facing incurable suffering, is overwhelmingly favoured in both England and Wales, it is relevant to note that a 2019 poll from NatCen found that whilst 88% of people in England favoured assisted dying for the incurably suffering, in at least some circumstances; this increased to 93% when respondents were asked from Wales. Given that the general purpose of devolution is to recognise that the Welsh electorate may have a different view to the rest of the UK, and thus should also be entitled to legislate on that matter differently; it surely follows that if the Welsh electorate has a different view on a morally subjective question, the importance of the Senedd's ability to legislate on that issue becomes all the more significant. Wales' inability to legislate in accordance with the wishes of its electorate is therefore unjust, and this is compounded by the fact that it is the sole administration where this is the case.

But more than this, even if the Welsh electorate did not want to change the law on assisted dying, the stark injustice of the Senedd's inability to make that choice must be exacerbated by the fact that Westminster has an effective veto. For example, under the current constitutional arrangements the Suicide Act 1961 (which prohibits assisted dying in England and Wales) can only be changed with the support of 326 MPs (or a simple majority) in Westminster. It is therefore impossible for the electorate in Wales, which has a different perspective to the electorate in England, to ever enact a change in the law, or conversely prevent a change in the law, since only 40 MPs represent Welsh constituencies. In short, this means any change in the law for Wales will always be reliant upon the views of English voters or their elected representatives.

This means that whilst it is widely understood that different people may reasonably disagree about the legalisation of assisted; and in recognition of this, almost every devolved administration can determine its own law; the Senedd does not have this authority; despite an overwhelming majority of the public favouring assisted dying; and English voters having an effective veto over the law in Wales. In view of these factors, we believe it is wrong as a matter of principle that Wales cannot decide its own law on assisted dying.

2) The Senedd's inability to determine the legality of assisted dying risks undermining the overall effectiveness of end-of-life care.

As established above, it is the view of My Death, My Decision that the Senedd's inability to determine Wales' law on assisted dying is unjust in principle. However, we also believe that the piecemeal devolution of end-of-life choices in Wales also has serious practical implications.

2 In Northern Ireland the law on assisted dying is governed by Section 5, 12, 13, 13A, and 13B of the Criminal Justice (Northern Ireland) Act 1966. In Scotland there is no statutory offence to assist in the death of another and instead the practice is governed by Scotland's common law crime of homicide. In the Isle of Man assisted dying is prohibited under Section 2(1) of the Criminal Law Act 1981; in the case of the Jersey and Guernsey, both dependencies are entitled to pass primary legislation to change the law on assisted dying but would require royal sanction from the Privy Council Committee for the Affairs of Jersey and Guernsey. In contrast, Section 2(1) and 2(2A) of the Suicide Act 1961 prohibit assisted dying in both England and Wales.

3 *Ibid no.1*. However, the sample size for Wales was admittedly smaller than England.

It is the view of *My Death, My Decision* that, like palliative care, the option of a legal and safeguarded assisted death should be seen as a fundamental healthcare right. Consequently, we view both high-quality palliative care and legalised assisted dying as not mutually exclusive end-of-life choices, but as complementary forms of assistance which exist on a spectrum of end-of-life options. Given this, we believe that since Wales already has the authority to decide its own law and policy on some end-of-life issues, namely palliative care,⁴ it is plainly illogical that the Senedd does not have the same authority over other end-of-life issues, such as the legislation of assisted dying.

This is because, despite the best efforts of palliative professionals in Wales and record levels of investment in hospice care, we recognise that palliative medicine inevitably has limits. For the avoidance of any doubt, this is not to say that access to palliative care does not need further expansion, nor that there isn't still more to be done in regard to its funding; it is merely a recognition that some forms of suffering and some medical conditions cannot be adequately alleviated by palliative care alone. For example, a recent study by the Office of Health Economics found that whilst only 1,048 people may die in Wales with completely unrelieved pain, nearly seven times more people (7,137) die with their pain only partially relieved, even if they might be receiving palliative assistance. Indeed, this problem is only likely to worsen as Wales' population grows older and more prone to comorbidity; as the Welsh Government's 'Future Trends Report' indicates is likely, since by 2039 the number of people aged over 65 in Wales is estimated to be 40% higher than it was in 2014.

In view of this, we believe that the overall effectiveness of Wales' end-of-life care regime may be undermined by the Senedd's inability to legislate and regulate assisted dying. This is because in jurisdictions where assisted dying is legal, there is evidence that the option of an assisted death can often help to resolve some of the limitations within palliative medicine. For example, since palliative medicine is a pain-oriented form of treatment, it is often ill-equipped to resolve other forms of suffering that are of an existential character e.g. loss of autonomy. But data from Oregon, which shows that a third of all applicants who apply for an assisted death do not then proceed after being accepted, implies that legal assisted dying may be capable of resolving these tensions and even encourage people to continue receiving palliative care.

In the experience of *My Death, My Decision*, many people who have been 'greenlighted' for an assisted death in Switzerland report that the mere knowledge that they could end their life if their suffering became unbearable is enough for them to continue living. Therefore, just as Northern Belgium has demonstrated for over a decade, we believe that end-of-life care works best when both palliative care and legal assisted dying exist in tandem. For example, over 70% of people who request an assisted death in the Flanders Region of Belgium will have exhausted the options of palliative care beforehand; as in Oregon, nearly 90% of patients receive palliative care before requesting assistance to die.

Because of this, we believe that it does not make sense for Wales to be prevented from deciding its own law on assisted dying, as the inability to provide one form of end-of-life assistance may arguably undermine the overall effectiveness of its care strategy.

4 Marie Curie, 'Palliative care and the UK nations: an updated assessment needs, policy, and strategy: implications for Wales'. Accessible at: <https://www.mariecurie.org.uk/globalassets/media/documents/policy/marie-curie-reports/state-of-the-nation-report-wales-english.pdf>

5 Indeed in jurisdictions which have legalised assisted dying, notably Canada, it is often the case that access and funding for palliative care is also improved alongside any change in the law. Given that legal assisted dying often results in end-of-life conversations becoming destigmatized, it is vital that palliative care is improved in conjunction with legal assisted dying to ensure that people make informed decisions based on all available options.

6 B. Zamora *et al*, 'Unrelieved Pain in Palliative Care in England', The Office of Health Economics (2019). Accessible at: <https://www.ohe.org/publications/unrelieved-pain-palliative-care-england>

7 Hospice UK, 'Hospice Care in Wales 2018' (2018). Accessible at: [https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/hospice-care-in-wales-report-2018-\(english\)_web.pdf?sfvrsn=2](https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/hospice-care-in-wales-report-2018-(english)_web.pdf?sfvrsn=2)

8 It is worth noting that in jurisdictions which have legalised assisted dying, the single most common reason for seeking an assisted death is 'losing autonomy' (on average 90.6% of applicants in Oregon), closely followed by a loss of dignity (74.4% on average) and inability to engage in activities which made life enjoyable (89.1% on average). In contrast, doctors in Oregon note only 25.7% of applicants on average are motivated by inadequate pain relief, which suggests assisted dying is not sought because of inadequate pain relief but rather due to other non-pain forms of suffering. Indeed, this has been affirmed by a recent investigation in Canada, which concluded it was unlikely applicants seek an assisted death because of inadequate access to palliative care. See n8, and J Downar *et al*, 'Early experience with medical assistance in dying in Ontario, Canada: a cohort study', *CMAJ* February 24, 2020 192 (8) E173-E181. Available at: <https://www.cmaj.ca/content/192/8/E173>

9 Oregon Health Authority, 'Oregon Death with Dignity Act: Data Summary 2018', Public Health Division, Centre for Health Statistics (2019). Accessible at: <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf>

10 S Dierickx *et al*, 'Involvement of palliative care in euthanasia practice in a context of legalized euthanasia: A population-based mortality follow-back study', *Palliat Med.* 2018 Jan; 32(1):114-122, accessible at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5758933/>

11 *Ibid* no.9

3) The prohibition of assisted dying in England and Wales seems to have a disproportionate impact on Wales.

In contrast to 10 jurisdictions in the United States of America, the Australian states of Victoria and Western Australia, Colombia, Switzerland, the Netherlands, Belgium, Luxembourg, Germany, Italy, and Canada, where assisted dying is permitted in some form, assisted dying remains unlawful in Wales and the rest of the UK. Indeed, under Section 2(1) and 2(2A) of the Suicide Act 1961 anyone found guilty of assisting another to die can face up to 14 years imprisonment.

Yet, despite the current blanket ban on assisted dying, research from the UK Assisted Dying Coalition, of which My Death, My Decision is a founding member,¹² has discovered that more than one person a week now travels from the UK to Switzerland for an assisted death.

In our view, these findings show that the current law in England and Wales does not work – and instead drives those who are either terminally ill or facing incurable suffering overseas or underground. Further statistics released to us indicate that the current ban may also have a disproportionate impact on Wales:

- The proportion of people who travel from Wales to Switzerland for an assisted death is one of the fastest growing demographics; and since 2014 the number of people who travel from Wales has more than doubled.
- Relative to Wales' population as a percentage of the United Kingdom, there have been multiple years where those who travel from the UK for an assisted death have disproportionately resided in Wales.¹⁴

Whilst it may be too early to make definitive observations, we believe that the mere risk that the Suicide Act 1961 may in practice have disproportionate consequences for Wales warrants the Senedd the ability to investigate and regulate its own law.

Therefore, as an area of concern, we recommend that the Senedd should request for the specific issue of assisted dying to fall within its devolved competencies.

In sum, we think that it is time for Wales to take a leading stance on legal, safe, and compassionate assisted dying for the incurably suffering and terminally ill, as Wales has done on similar issues beforehand. We of course recognise that others may disagree. Yet, given that the current law :

- (i) unjustly denies Wales the same competencies as other devolved administrations; and
- (ii) (having regard to other matters already devolved) wrongly divorces in Wales a key element from the overall spectrum of end-of-life care, of which it should properly form part; and
- (iii) may disproportionately impact upon people living in Wales,

we believe that there is a strong case for Wales have at the very least the authority to determine its own law.

Hence, we strongly recommend that the Senedd requests for Westminster to devolve the specific justice matter of assisted dying to the Senedd.

¹² Assisted Dying Coalition, 'Briefing: Number of UK citizens going to Switzerland to seek an assisted death' (2018). Accessible at: https://humanism.org.uk/wp-content/uploads/2019-2-1-KM-Assisted-Dying-Briefing_-_Number-of-UK-citizens-going-to-Switzerland-to-seek-an-assisted-death-1.pdf

¹³ According to statistics released to My Death, My Decision nine people travelled from Wales to Dignitas between 2002 and 2013. This accounts on average for 0.6 visitors per year. In comparison, between 2014 and 2020 we understand that eight people travelled to Dignitas, accounting for an average of 1.3 visitors every year.

¹⁴ According to EuroStat and figures from the Office of National Statistics, Wales' population accounted for 5.9% of the UK in 2014, but 6.8% of those travelling from the UK to Dignitas in the same year. Equally, in 2017, Wales' population accounted for 5% of the UK, but 5.8% of those travelling for an assisted death in 2017.