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My Death, My Decision's submission to

The Independent Commission on the Constitutional Future of Wales.

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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. We have hundreds of members and thousands of supporters all over the UK and crown dependencies. Our organisation also has local groups (including in Cardiff) run by volunteers. My Death, My Decision's local groups run campaigns and raise awareness in their local areas.

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 suffering from incurable physical conditions. Accordingly, we believe that legalised assisted dying should not be restricted to only those with six or fewer months left to live. 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.

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1. What matters to you about the way Wales is run?

My Death, My Decision believes that Wales should be run in a way which enables the Welsh people to live with dignity and in full autonomous control over their own lives. Currently, an archaic law dictated by Westminster prevents the Senedd legislating on assisted dying. Under Section 2 of the *Suicide Act 1961*, assisted dying is a criminal offence in England and Wales¹. The powers of justice and policing are not devolved

¹ Suicide Act 1961. Section 2. Available here: https://www.legislation.gov.uk/ukpga/Eliz2/9-10/60/section/2

to Wales and so the Senedd is unable to legislate in support of legalising assisted dying². This sets Wales apart from Scotland's devolved parliament which can legislate on this issue as demonstrated by the proposed bill: Assisted Dying for Terminally III Adults (Scotland) Bill³. My Death, My Decision argues that this is a fundamental issue with respect to the legislative sovereignty of Wales which is in need of immediate resolution, because it is inextricably linked with health and social care (discussed below). We hope that with the power to legislate, Wales would legalise the option of assisted dying for those who are either terminally ill or intolerably suffering and seeking to end their life with dignity and on their own terms.

As health is a devolved matter, the Senedd can legislate on matters such as palliative care and organ donation. These two areas are particularly noted, as palliative care is intrinsically linked to assisted dying and the two areas should work in tandem to support better health outcomes⁴. For example, over 70% of people who request an assisted death in the Flanders Region of Belgium will have already exhausted the options of palliative care, while in Oregon, nearly 90% of patients receive palliative care before requesting assistance to die⁵.

Organ donation has previously been considered a health issue with ethical questions similar to assisted dying. Progressive health policy by Wales with regards to organ donation has allowed the nation to lead the way for the rest of the UK to help improve health outcomes⁶. My Death, My Decision suggests that the Senedd should petition Westminster to recognise that assisted dying should fall under its devolved health remit. Assisted dying is not some fringe or radical concept, it is legal in many jurisdictions and an available option to over 350 million people. It is an outdated stigma to criminalise assisted dying instead of treating it as a form of compassionate and necessary end-of-life choice within healthcare, and so there is no reason why assisted dying should remain out of reach from Welsh health policy competency. Our position is that this compassion should be available to Welsh residents who are terminally ill, as well as those who suffer from incurable conditions in a way which they consider to be intolerable.

2. What do you think the priorities for the commission should be?

The issue of Assisted Dying in Wales cannot be resolved by the Welsh government and Senedd according to the wishes of the Welsh people under the current constitutional arrangement. Many Welsh people who are terminally ill or intolerably suffering may wish to have help to end their own life but are unable to do so. We believe it is an affront to basic human dignity and the spirit of human rights⁷ that these people have no legal choice but to suffer interminably, leaving themselves and

² Senedd Cymru Welsh Parliament. (2021). Powers. Available here: https://senedd.wales/how-we-work/our-role/powers/

³ MacArthur, L. (2021). Proposed Assisted Dying for Terminally III Adults (Scotland) Bill. Available here:

https://www.parliament.scot/bills-and-laws/proposals-for-bills/proposed-assisted-dying-for-terminally-ill-adults-scotland-bills.

⁴ My Death, My Decision. (2022). Senedd. Available here: https://www.mydeath-mydecision.org.uk/senedd/

⁵ My Death, My Decision. (2022). Making Justice Work in Wales: A response from My Death, My Decision. Available here: https://www.mydeath-mydecision.org.uk/wp-content/uploads/2021/04/Making-Justice-work-in-Wales-Consultation-Response-from-My-Decision.pdf

⁶ Welsh Government. (2019). Wales leading the way on organ donation. Available here: https://www.gov.wales/wales-leading-way-organ-donation

My Death, My Decision. (2021). Independent Human Rights Act Review: A Response From My Death, My Decision. Available here: https://www.mydeath-mydecision.org.uk/wp-content/uploads/2021/04/Independent-Human-Rights-Act-Review-1.pdf

their loved ones traumatised and in severe pain. The lack of provision for assisted dying can put great strain on relationships as those close to the terminally ill or intolerably suffering person are caught between wanting to help fulfil their friend's or family member's wishes and risking a considerable prison sentence.

The legalisation of assisted dying should be seen as a priority for a humane, civilised, and compassionate society which recognises that death is an intrinsic part of life. The criminalisation of assisted dying discriminates against those who are unable to travel to another jurisdiction to end their life on their own terms, and can force those who seek to end their life to attempt to do so in an unsafe and painful way, such as through starvation. Research has estimated that at least one UK resident a week travels to Switzerland to end their life via assisted suicide⁸, and suggests Welsh residents are disproportionately represented in making this journey compared to the rest of the UK⁹.

The Senedd, despite lacking legislative competency, has previously debated the legalisation of assisted dying and voted against it. We believe that this is an issue which requires revisiting, as the previous vote in 2014 (12 for, 21 against, and 20 abstaining) is massively unrepresentative of the current views of the Welsh public¹⁰. The legalisation of assisted dying is a proposition which receives overwhelming support from the people of Wales. Research has found that public support for the legalisation of assisted dying in Wales is an extremely high 93%, higher than the 90% support legalisation enjoys in England¹¹.

The criminalisation of suicide and other related actions has typically stemmed from the intersection of religious moral belief and policy making¹². Wales is considerably less religious than England with 46.5% of the population reporting as belonging to no religion compared to 36.7% in England¹³. Therefore, the Senedd should acknowledge this support that assisted dying enjoys, vote accordingly in its favour, and thereby pressure Westminster into acting democratically and releasing the legislative competency to Wales. This could be through Westminster repealing its dated legislation in the *Suicide Act 1961*, therefore decriminalising assisted dying and allowing the Senedd to create a law under the devolved competency of health governing assisted dying which is modern, draws on experience from other jurisdictions, and receives the support of the people of Wales. Alternatively, as in Scotland and Northern Ireland, Westminster could further devolve powers of justice

⁸ Assisted Dying Coalition. (2021). Briefing: Number of UK Citizens going to Switzerland to seek an assisted death. Available here:

https://www.mydeath-mydecision.org.uk/wp-content/uploads/2021/04/Number-of-UK-citizens-going-to-Switzerland-to-seek-anassisted-death-1.pdf

⁹ My Death, My Decision. (2022). Making Justice Work in Wales: A response from My Death, My Decision. Available here: https://www.mydeath-mydecision.org.uk/wp-content/uploads/2021/04/Making-Justice-work-in-Wales-Consultation-Response-from-My-Decision.pdf

¹⁰ Shipton, M (2014). 'Assisted dying' proposal defeated in National Assembly after gaining support of just 12 AMs". Wales Online. Available here: https://www.walesonline.co.uk/news/wales-news/assisted-dying-proposal-defeated-national-8268159

¹¹ My Death, My Decision. (2022). Senedd. Available here: https://www.mydeath-mydecision.org.uk/senedd/

¹² Pew Research Center. (2013). Religious Groups' Views on End-of-Life Issues. Available here: https://www.pewresearch.org/religion/2013/11/21/religious-groups-views-on-end-of-life-issues/

¹³ Census 2021 (2022). Religion, England and Wales: Census 2021. Available here:

https://www.ons.gov.uk/people population and community/cultural identity/religion/bulletins/religionen gland and wales/census 2021

and policing to the Senedd and assisted dying could then be decriminalised in Wales by the Senedd.

Thankfully, relatively few cases of assisted dying in the UK are prosecuted¹⁴. CPS quidelines suggest that "suspects" are less likely to be prosecuted if they were wholly motivated by compassion and the "victim" had reached a voluntary, clear, settled and informed decision to commit suicide¹⁵. However, cases such as Sue Lawford's show that these guidelines are inconsistently applied. On 14th February 2022, Sharon Johnston, a tetraplegic following an unfortunate accident, travelled to Dignitas in Switzerland to end her life and was accompanied by Sue Lawford. The two Welsh residents were subject to stress upon arrival due to being visited by armed Swiss police, believed to be after an alert by Dyfed Powys Police¹⁶. Johnston was positively assessed by a psychiatrist and doctor on whether she could make a rational decision in ending her life, and subsequently died peacefully on the 15th February. Sue Lawford returned to Wales and was arrested at 5.30am on the 16th February, interrogated by police, detained for 19 hours, and then subjected to a six-month investigation which has since been dropped¹⁷. Sue's arrest was especially inappropriate given that previous police guidelines have stated: "Due to the sensitive nature of such an investigation, the police should seek to interview such a suspect under caution as a voluntary attendee unless their lack of cooperation or demeanour makes arrest necessary"18.

It is wrong that people like Sue Lawford should be arrested, detained, and prosecuted for displaying compassion towards other Welsh residents and helping them take autonomous control over their own lives. Decriminalising assisted dying as an option for those who are terminally ill or intolerably suffering is the solution to these injustices. The current constitutional arrangement affects the human rights of Welsh citizens because the Senedd has no authority to decriminalise assisted death in Wales. My Death, My Decision suggests that the commission should focus on how it is detrimentally affecting the human and health rights of the Welsh people.

3. Thinking about how Wales is governed, by the Welsh Government and the UK government, what are the strengths of the current system, what aspects do you most value and wish to protect? Can you provide examples?

The theoretical strength of the United Kingdom is that it is a union of equals¹⁹, one which is then able to produce value greater than the sum of its parts. However, if the devolved governments within the United Kingdom are not treated equally, it becomes difficult to argue that the union is one based on equality. The various nations within the United Kingdom share many things, but Wales, England, Scotland, and Northern

¹⁴ CPS. (2022). Assisted Suicide. Available here: https://www.cps.gov.uk/publication/assisted-suicide

¹⁵ The Director of Public Prosecutions. (2014). Suicide: Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide. Section 45. Available here:

https://www.cps.gov.uk/legal-guidance/suicide-policy-prosecutors-respect-cases-encouraging-or-assisting-suicide ¹⁶ Lewis, F. (2022). 'I helped a stranger die and was arrested when I got off the plane'. Wales Online. Available here: https://www.walesonline.co.uk/news/wales-news/dignitas-assisted-dying-law-uk-25531319

¹⁷ HumanistsUK. (2022). Humanist subjected to six-month investigation over assisted death. Available here: https://humanists.uk/2022/11/15/humanist-subjected-to-six-month-investigation-over-assisted-death/

¹⁸ Association of Chief Police Officers' Guidelines on Dealing with Cases of Encouraging or Assisting Suicide in paragraph 4.7.9
¹⁹ Welsh Government. (2021). Reforming our Union 2021: summary. Available here:

https://www.gov.wales/reforming-our-union-shared-governance-in-the-uk-2nd-edition-summary-html

Ireland also enjoy unique characteristics; and so there should be no justification for one devolved government being withheld a key legislative competency. My Death, My Decision believes that the people of Wales should have the power to turn their belief in the legalisation of assisted dying into law, just as the people of Scotland are able to do. In the unlikely situation that Welsh public opinion was to change on assisted dying, it should still be the people of Wales that make this decision and not Westminster²⁰.

4. Are there any problems with the current system, and if so, how could they be addressed? Again, please provide examples.

In 2021, the Welsh government published the report *Reforming Our Union 2021*²¹. Included in this report were 20 points as to how the UK can better work for all nations. We suggest that the way in which legislative competency over assisted dying is withheld by Westminster is in breach of at least four of these points:

- 4. "The UK Parliament should not normally make law in relation to matters, which are decided on in another part of the UK without express consent. These arrangements must be properly set out.
- 8. The relationship between the 4 governments in the UK the UK government, the Scottish Government, the Welsh Government and the Northern Ireland Executive should be based on a partnership of equals, mutual respect and be fair.
- 10. There should be well-organised and regular opportunities for governments to work together on shared issues for the good of all people in the UK
- 18. Justice and policing should be devolved to Wales as it is to Scotland and Northern Ireland."

My Death, My Decision suggests that pushing for the legalisation of assisted dying would act as a symbolic representation of the Welsh Government's intention to achieve more devolution and become an equal member of the United Kingdom.

5. Thinking about the UK government, the Welsh Government and Welsh local government (your local council), what do you think about the balance of power and responsibility between these 3 types of government – is it about right or should it change and if so, how? For example, who should have more power, or less?

My Death, My Decision advocates for the legalisation of assisted dying across both England and Wales. We argue that it is inappropriate that Westminster should

²⁰ My Death, My Decision. (2022). Making Justice Work in Wales: A response from My Death, My Decision. Available here: https://www.mydeath-mydecision.org.uk/wp-content/uploads/2021/04/Making-Justice-work-in-Wales-Consultation-Response-from-My-Decision.pdf

²¹ Welsh Government. (2021). Reforming our Union 2021: summary. Available here: https://www.gov.wales/reforming-our-union-shared-governance-in-the-uk-2nd-edition-summary-html

undemocratically cordon off the competence to legislate over assisted dying from Wales, thereby denying the Senedd the ability to follow the wishes of the majority of Welsh people.

6. As a distinct country and political unit, how should Wales be governed in the future? Should we:

- broadly keep the current arrangements where Wales is governed as part of the UK, and the Westminster Parliament delegates some responsibilities to the Senedd and Welsh Government, with those responsibilities adjusted as in Q5, OR
- move towards Wales having more autonomy to decide for itself within a more federal UK, with most matters decided by the Senedd and Welsh Government, and the Westminster Parliament decides UK-wide matters on behalf of Wales (and other parts of the UK) OR
- move towards Wales having full control to govern itself and be independent from the UK OR
- pursue any other governance model you would like to suggest
- alongside any of these options, should more responsibilities be given to local councils bringing decision making closer to people across Wales and if so, please provide examples.

Within the UK, it seems both inappropriate and undemocratic that assisted dying should be a reserved matter in one nation, and a devolved matter in another.

7. Overall, what is most important to you in about the way in which Wales should be governed in the future? Is there anything else you want to tell us?

Wales should be governed in a way where the nation's devolved powers can be used to better represent the will of the Welsh people. It is undeniable that the legalisation of assisted dying is a key part of this will, and so legalisation should be a matter of priority. The terminally ill and intolerably suffering people of Wales, as well as their loved ones, should no longer be faced with a choice of misery and trauma, or prosecution. My Death, My Decision urges the Welsh Government to do all it can to see this injustice be rectified.