Assisted Dying for Terminally III Adults (Scotland) Bill

Liam McArthur MSP

A proposal for a Bill to enable competent adults who are terminally ill to be provided at their request with assistance to end their life.

Consultation by Liam McArthur MSP, Scottish Liberal Democrat Member for Orkney Islands

22 September 2021

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#### **Foreword**



I have long believed that the people of Scotland should be able to access safe and compassionate assisted dying if they choose, rather than face the potential of a prolonged and painful death.

For the purposes of this consultation, Assisted Dying means the practice whereby a person diagnosed with a terminal illness is given the choice to end their own life, by means of medication provided by a doctor for that purpose.<sup>1</sup> At present, this risks charges for a

number of possible offences in Scots criminal law.

The current prohibition on such assistance is unjust and causes needless suffering for many dying people and their families across Scotland. If a person has reached the limits of palliative care and faces a bad death, none of the current options available to them in Scotland are likely to provide an acceptable alternative.

The proposal presented in this Consultation is one that co-exists with support for more and better palliative care and applies only to terminally ill, mentally competent adults. It has strong safeguards that put transparency, protection and compassion at its core and is modelled on legislation that has passed rigorous testing in other countries around the world.

It is a proposal that chimes with powers our Parliament has to deliver change that will help build a fairer and more progressive society. Emerging from the pandemic, we have an opportunity to take the actions required to make sure that the end of life is more compassionate, fairer and more reflective of a dying person's choice. We have the ability to create a new standard for how we die.

Sadly, it is the case that too many Scots still face a bad death, some enduring physical and emotional suffering even when high-quality specialist palliative care is present. This proposal complements excellent palliative care and builds upon it but recognises that there are limits to what can be achieved and that an estimated 11 Scots a week die badly in spite of such care.<sup>2</sup> We can and must do better for our dying citizens and their

<sup>&</sup>lt;sup>1</sup> There is no universally agreed definition of assisted dying, we feel that it is appropriate to use assisted dying as the umbrella term here but note that previous attempts (Assisted Suicide (Scot) Bill) referenced assisted suicide, and that internationally it can be referred to as medical aid in dying, physician-assisted death *inter alias*. The use of 'suicide' in this context is not appropriate, given that the person will only be able to request an assisted death if they have a terminal illness that will end their life i.e. the choice to live has already been taken away, the choice of an assisted death allows the inevitable dying process to be less traumatic.

<sup>&</sup>lt;sup>2</sup> Dignity in Dying, The Inescapable Truth about Dying in Scotland (2019) at: <a href="https://features.dignityindying.org.uk/inescapable-truth-scotland/">https://features.dignityindying.org.uk/inescapable-truth-scotland/</a>

families. This is the conclusion being reached by more and more people in Scotland, often prompted by the anguish of witnessing the bad death of a loved one.

During the 2021 Scottish Parliament election campaign, many candidates heard from thousands of people living in Scotland who wanted us to act on this issue. Assisted dying also featured in political parties' manifestos, with commitments to explore the issue in this session of Parliament.<sup>3</sup> I believe this is an issue where cross-party consideration can play a valuable role in making the final proposal as robust as possible, and I look forward to engaging with my colleagues across the political spectrum.

I know from my own mailbag that the demand for change is growing and that people across Scotland want MSPs to take action to prevent suffering and extend compassionate end of life choices to include assisted dying. It is an issue that is not going away and one which this Consultation seeks to address. Over my own journey, I have learned many lessons and, most importantly, listened to the stories of those with lived experience who have been denied this choice. A consideration of the lived experiences of our citizens alongside the available research, both nationally and internationally, shows that assisted dying laws can be implemented safely and successfully, and concerns can be addressed by implementing robust safeguards.

In an international context, over 200 million citizens worldwide now have access to assisted dying.<sup>4</sup> Given the reputation of Scotland and its Parliament for embracing progressive values of justice, rights, equity, and compassion, I believe it is only right that this Consultation seeks to find a Scotland-specific approach to legislate for the choice of an assisted death for terminally ill adults.

In many ways this is unfinished business for the Scottish Parliament and I pay tribute to the late Margo MacDonald MSP,<sup>5</sup> Patrick Harvie MSP<sup>6</sup> and Jeremy Purvis MSP<sup>7</sup> for their efforts in advancing this debate in previous parliamentary sessions. They have shown that an outright prohibition does not work and that we cannot continue to tolerate a situation where the options open to people at the end of life are so limited.

https://issuu.com/hinksbrandwise/docs/04\_15\_snp\_manifesto\_2021\_\_\_a4\_document?mode=window;
Scottish Greens Manifesto (2021) at page 66 see: ScottishGreens\_2021Manifesto\_Full\_web\_version.pdf

4 Assisted dying: a question of when, not if. BMJ 2021; 374 doi: https://doi.org/10.1136/bmj.n2128

<sup>&</sup>lt;sup>3</sup>SNP Manifesto (2021) at page 13 see:

<sup>(</sup>Published 09 September 2021)

<sup>&</sup>lt;sup>5</sup> End of Life Assistance (Scotland) Bill 2010 at:

https://archive2021.parliament.scot/parliamentarybusiness/bills/21272.aspx#:~:text=A%20Bill%20to%20permit%20assistance,ended%3B%20and%20for%20connected%20purposes.&text=The%20Parliament%20disagreed%20to%20the,and%20the%20Bill%20therefore%20fell.

<sup>&</sup>lt;sup>6</sup> Assisted Suicide (Scotland) Bill 2013 at:

https://archive2021.parliament.scot/parliamentarybusiness/bills/69604.aspx

<sup>&</sup>lt;sup>7</sup> Dying with Dignity Consultation (2005) at:

 $<sup>\</sup>underline{https://archive2021.parliament.scot/S2\_MembersBills/Draft%20proposals/Dying%20with%20Dignity%20C}\\\underline{onsultation\%20paper.pdf}$ 

This Consultation and proposed future Bill build on that work but differ from previous legislative proposals in that they are more limited in scope.<sup>8</sup> The intention is for the choice to be available to mentally competent and terminally ill adults only.<sup>9</sup> I understand that some people hold different views but ask that they consider the issue in light of the evidence and actual proposals put forward here. This is a progressive reform that puts in place safeguards where none currently exist. In that sense, it is a protective measure.

Above all, it seeks to give peace of mind, comfort, and reassurance to those who need it most i.e. those who are suffering and dying.

In bringing forward a similar Bill in the House of Commons in 2014, Labour peer Charles Falconer set out very well the problem that this Consultation and proposed Bill seek to remedy:

"In the last stages of a terminal illness, there are people who wish to end their life rather than struggle for the last few months, weeks, days or hours. Often it is not the pain that motivates such a wish, but the loss of independence and dignity...the current situation leaves the rich able to go to Switzerland, the compassionate treated like criminals and no safeguards in respect of undue pressure. Many people, caring so much for those they leave behind, are dying earlier and alone because they fear implicating their loved ones in a criminal enterprise."

I firmly believe that an end to the current blanket ban on the right to a compassionate death is long overdue and can be delivered in this session of Parliament. Indeed, I have no doubt that we will look back in future and wonder why we didn't act sooner.

For now, I urge you to engage with this consultation and help ensure that Scotland's laws in this area reflect the progressive, compassionate country we aspire to be.

Liam McArthur MSP, 22 September 2021

<sup>&</sup>lt;sup>8</sup> The Assisted Suicide (Scotland) Bill 2013 applied to people with terminal or life-shortening illnesses or progressive conditions which are terminal or life-shortening. s 8 (5).

<sup>&</sup>lt;sup>9</sup> It is Scottish Government policy, supported by the members of the Scottish Parliament, to define terminal illness, for the purposes of providing social security, as that suffered by those deemed by doctors as 'unable to recover', regardless of the time they have left to live. This was thoroughly considered and decided upon during the passing of the Social Security (Scotland) Act 2018. Under the previous system, a claimant was not deemed to be suffering from a terminal illness unless medics considered that they had six months or less to live. As regards the definition of terminal illness, see also: Hui, David et al. "Concepts and definitions for "actively dying," "end of life," "terminally ill," "terminal care," and "transition of care": a systematic review." *Journal of pain and symptom management* vol. 47,1 (2014): 77-89. doi:10.1016/j.ipainsymman.2013.02.021

<sup>&</sup>lt;sup>10</sup> Hansard (HL) Assisted Dying Bill, Col 775, 18 July 2014.

#### How the Consultation Process works

This consultation relates to a draft proposal I have lodged as the first stage in the process of introducing a Member's Bill in the Scottish Parliament. The process is governed by Chapter 9, Rule 9.14, of the Parliament's Standing Orders which can be found on the Parliament's website at:

https://parliament.scot/parliamentarybusiness/17797.aspx

At the end of the consultation period, all the responses will be analysed. I then expect to lodge a final proposal in the Parliament along with a summary of those responses. If that final proposal secures the support of at least 18 other MSPs from at least half of the political parties or groups represented in the Parliamentary Bureau, and the Scottish Government does not indicate that it intends to legislate in the area in question, I will then have the right to introduce a Member's Bill. A number of months may be required to finalise the Bill and related documentation. Once introduced, a Member's Bill follows a 3-stage scrutiny process, during which it may be amended or rejected outright. If it is passed at the end of the process, it becomes an Act.

At this stage, therefore, there is no Bill, only a draft proposal for the legislation.

The purpose of this consultation is to provide a range of views on the subject matter of the proposed Bill, highlighting potential problems, suggesting improvements, and generally refining and developing the policy. Consultation, when done well, can play an important part in ensuring that legislation is fit for purpose.

The consultation process is being supported by the Scottish Parliament's Non-Government Bills Unit (NGBU) and will therefore comply with the Unit's good practice criteria. NGBU will also analyse and provide an impartial summary of the responses received.

Details on how to respond to this consultation are provided at the end of the document.

Additional copies of this paper can be requested by contacting me at **Liam McArthur MSP**, **The Scottish Parliament**, **Edinburgh**, **EH99 1SP**; **telephone**: 0131 348 5815; <u>Liam.McArthur.msp@parliament.scot</u>

British Sign Language (BSL) and Easy Read versions of this document have also been produced and can be accessed at <a href="https://www.assisteddying.scot">www.assisteddying.scot</a>

Enquiries about obtaining the consultation document in any language other than English or in further alternative formats should also be sent to me.

An on-line copy is available on the Scottish Parliament's website (www.parliament.scot) under Parliamentary Business / Bills / Proposals for Members' Bills.

## 1 Aim of the Proposed Bill

The aim of the proposal is to enable mentally competent adults who are terminally ill to be provided with assistance to end their life at their request.

In Scotland, a person is terminally ill if a registered medical practitioner has diagnosed them as having a progressive disease, which can reasonably be expected to cause their death.<sup>11</sup>

The person must be 16 years of age or over, which is the age of majority<sup>12</sup> in Scotland, and have been a resident of Scotland for at least twelve months.<sup>13</sup>

## 1.1 Safeguards

We are keen to hear views on safeguards that should be considered for inclusion in this Bill proposal. In line with the information contained within this document, the following list of safeguards have been identified and would apply before someone ends their life.

- Two doctors independently confirm the person is terminally ill.
- Two doctors establish that the person has the mental capacity to request an assisted death.
- If either doctor is unsure about the person's capacity to request an assisted death, the person is referred to a psychologist or other appropriate specialist.
- Two doctors assess that the person is making an informed decision without pressure or coercion.
- Two doctors ensure the person has been fully informed of palliative, hospice, and other care options.
- The person signs a written declaration of their request, which is witnessed and signed by both doctors.
- A suggested waiting period of 14 days allows the person time to reflect on their decision. This timeframe is shorter if the person is expected to die within 30 days.
- The life-ending medication is stored at a pharmacy and is delivered to the person by a registered healthcare practitioner (HCP).
- An HCP brings the medication, checks the person continues to retain their capacity, and a settled intention to die, and remains present.
- The person must administer the life-ending medication themselves.

<sup>11</sup> Scottish Government, Social Security Policy, Terminal Illness <a href="https://www.gov.scot/policies/social-security/terminal-illness/">https://www.gov.scot/policies/social-security/terminal-illness/</a> Whilst this is a specific policy adopted for a specific purpose, it is generally agreed as a reasonable definition and has been adopted for the purposes of this consultation.

<sup>&</sup>lt;sup>12</sup> The term 'age of majority' refers to when a person reaches the age where one is considered to be an adult.

<sup>&</sup>lt;sup>13</sup> This differs from the End of Life Assistance (Scotland) 2010 Bill which stated 18 months and the Assisted Suicide (Scotland) 2013 Bill where no time was detailed. Having reviewed international procedures, twelve months was settled on as most appropriate.

- It would continue to be a criminal offence to end someone's life directly.
- Every assisted death would be recorded and reported for safety, monitoring, and research purposes.

## 2 Background

#### 2.1 The law

Throughout the UK, a person assisting in the death of another risks being charged with criminal offences.

In Scotland, there is no distinct legislation that governs ending your own life or assisted dying.

The scope of the law in England and Wales (E&W) and in Northern Ireland (NI) is broader than in Scotland. In E&W under the Suicide Act 1961, and in NI under the Criminal Justice Act 1966,<sup>14</sup> it is not a crime to take your own life, but it is a crime to encourage or assist suicide.<sup>15</sup> The legislation in England, Wales and Northern Ireland does not apply to Scotland.

In Scotland, there is no equivalent legislation, thus while assisted dying is not, in itself, a specific criminal offence in Scotland, assisting the death of another may give rise to liability for either murder or culpable homicide where there is requisite intention and a causal link. While the Court of Session has held that "it is not a crime to assist in a suicide" in Scotland – and this includes "taking persons to places where they may commit, or seek assistance to commit, suicide" – the legal position for other forms of physical assistance which a medic, family member or friend may give to a terminally ill person remains unclear. The Lord Advocate in Scotland has indicated that where there is sufficient evidence that a homicide has occurred, they would regard such actions as deliberate killing, and thus a charge of murder or culpable homicide could be brought. This approach generates considerable uncertainty about what conduct is and is not lawful, exposing anyone who assists a family member, friend or patient to end their life to the risk of being indicted for murder or culpable homicide if their assistance appears to the prosecutor to be the "immediate and direct cause" of death.

<sup>&</sup>lt;sup>14</sup> Section 13 of the Criminal Justice Act (Northern Ireland) 1966.

<sup>&</sup>lt;sup>15</sup> Section 2(1) of the Suicide Act 1961 (as amended by section 59(2) of the Coroners and Justice Act 2009).

<sup>&</sup>lt;sup>16</sup> MacAngus v HM Advocate LJG (Hamilton) at para [42].

<sup>&</sup>lt;sup>17</sup> Ross v Lord Advocate (2016] CSIH 12 at paragraphs 29 and 31 accessible here: https://www.scotcourts.gov.uk/search-judgments/judgment?id=363108a7-8980-69d2-b500-ff0000d74aa7

<sup>&</sup>lt;sup>18</sup> The Lord Advocate. Written submission to Scottish Parliament Justice Committee at para 24 of Stage 1 Report on Assisted Suicide (Scotland) Bill, 6<sup>th</sup> Report, 2015 (Session 4).

<sup>&</sup>lt;sup>19</sup> MacAngus v HM Advocate LJG (Hamilton) at para [42].

Prosecutors in E&W<sup>20</sup> and NI<sup>21</sup> have produced specific guidelines on when they would choose to prosecute following the case of *R (Purdy) v DPP*, establishing that Human Rights legislation requires prosecutors to issue guidance about the circumstances in which they will prosecute people who assist others to take their own lives.<sup>22</sup> The Lord Advocate has declined to produce such specific guidelines.<sup>23</sup>

Legal certainty is one of the basic principles of the rule of law. Citizens should be able to understand what behaviour is and is not criminal in their country. Legal clarity is even more important in circumstances where individuals find themselves dealing with emotional, tragic, and often extremely difficult end of life choices. Leading legal experts have described the law on assisted dying as having an "alarming lack of clarity," raising basic questions about whether it is compatible with Scotland's international obligations under the European Convention on Human Rights.<sup>24</sup>

Worse, the status quo also lacks the appropriate safeguards and monitoring standards which all established assisted dying laws in other jurisdictions have incorporated in law, ensuring that the patient is central to all medical-treatment decisions.<sup>25</sup>

Leading criminal law academics in Scotland have characterised the status quo as a "shameful state of affairs" which "should embarrass any legal system."<sup>26</sup> Regius Professor of Law at the University of Glasgow, James Chalmers, has said that "I do not believe that the legal position can be clarified other than by legislation."<sup>27</sup>

## 2.2 Consequences of the current position

According to Dignity in Dying, pre-pandemic one person every eight days travelled from the UK to Switzerland in order to end their life,<sup>28</sup> and recent polling showed that over

<sup>&</sup>lt;sup>20</sup> CPS, Suicide: Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide See: <a href="https://www.cps.gov.uk/legal-guidance/suicide-policy-prosecutors-respect-cases-encouraging-or-assisting-suicide">https://www.cps.gov.uk/legal-guidance/suicide-policy-prosecutors-respect-cases-encouraging-or-assisting-suicide</a>

<sup>&</sup>lt;sup>21</sup> PPS, Policy on Prosecuting the Offence of Assisted Suicide.

See: Policy on Prosecuting the Offence of Assisted Suicide | Public Prosecution Service Northern Ireland (ppsni.gov.uk).

<sup>&</sup>lt;sup>22</sup> R (Purdy) v DPP [2009] UKHL 45.

<sup>&</sup>lt;sup>23</sup> Elish Angolini declined to produce guidelines after the *R (Purdy) v DPP* 2009 case and subsequent Lord Advocate's (Frank Mulholland, James Wolffe) have upheld this.

<sup>&</sup>lt;sup>24</sup> Herald Scotland (2015) "A troubling lack of clarity in Scots law regarding assisted suicide" See: <a href="http://www.heraldscotland.com/opinion/13208016.A\_troubling\_lack\_of\_clarity\_in\_Scots\_law\_regarding\_a\_sisted\_suicide/">http://www.heraldscotland.com/opinion/13208016.A\_troubling\_lack\_of\_clarity\_in\_Scots\_law\_regarding\_a\_sisted\_suicide/</a>.

<sup>&</sup>lt;sup>25</sup> Oregon Death with Dignity Act 127.815 - 127.865 section 3 safeguards; Criminal Code Canada Bill c-7 (2021), Chapter 2, Criminal Code, s. 241.2; Victoria Voluntary Assisted Dying Act 2017, Division 5 Reports s. 107 Annual Reports; New Zealand End of Life Choice Act 2019 Part 3 Accountability. <sup>26</sup> Herald Scotland (2015) "A troubling lack of clarity in Scots law regarding assisted suicide" See: <a href="http://www.heraldscotland.com/opinion/13208016.A">http://www.heraldscotland.com/opinion/13208016.A</a> troubling lack of clarity in Scots law regarding a ssisted suicide/.

<sup>&</sup>lt;sup>27</sup> Assisted Suicide (Scotland) Bill, Written Submission, Para 35.

<sup>&</sup>lt;sup>28</sup> The Inescapable Truth About Dying in Scotland, Dignity in Dying Scotland, 2019.

half the population in Scotland would consider travelling abroad for an assisted death if they had a terminal illness, or one which caused them incurable suffering.<sup>29</sup>

At least 20 Scottish citizens have died at Swiss facilities such as Dignitas.<sup>30</sup> Silvan Luley of Dignitas attended a Cross Party Group meeting at the Scottish Parliament and urged MSPs to change the law, as his organisation and others are oversubscribed and overburdened by terminally ill people travelling abroad, due to the lack of assistance to die in their own country.

The issue is one of transparency, accountability, safety and justice.<sup>31</sup> Scotland should not outsource this issue, driving it underground and away from the protective framework of the law.

There have been numerous cases in Scotland of loved ones assisting a relative to die.<sup>32</sup> These cases often go unreported or are considered by the Lord Advocate not to be in the public interest to prosecute. In the very few cases that do reach court, the result is often admonishment. Families are facing excruciating decisions on whether to assist a loved one to die, risking the prospect of life imprisonment.<sup>33</sup> Or conversely, they are fearful of acting, and as a result, must witness a loved one suffering unbearably. Currently, the only record kept of people's intent/motives is in relation to a potential police investigation after a person has been assisted to die. The distress caused by a lengthy investigation/consideration of a case for prosecution that is eventually dropped cannot be understated and compounds the existing suffering of the family as a result of the lack of legal clarity.

The Scottish Government does not hold information on the number of people who have assisted another to die. Should such an incident lead to the recording of a homicide by Police Scotland or the prosecution of an individual through the courts, it will be included in the National Statistics on Homicide or the National Statistics on Criminal Proceedings, respectively. However, the information received for these publications does not specify whether the homicide involved an individual assisting another to die. Therefore, we know anecdotally that people are increasingly taking the law into their own hands, either by helping a loved one to die or by taking their own life alone, ill-informed and often in violent and distressing ways, but we have no reliable record of

<sup>30</sup> Dignitas – To live with dignity – To die with dignity. Stats provided by Silvan Luley to Amanda Ward, PhD thesis, 4 Suicide Tourism.

<sup>&</sup>lt;sup>29</sup> Humanist Society Scotland 2018 polling. See: <a href="https://www.humanism.scot/wp-content/uploads/2017/09/Assisted-Dying-Poll-Data.pdf">https://www.humanism.scot/wp-content/uploads/2017/09/Assisted-Dying-Poll-Data.pdf</a>

<sup>&</sup>lt;sup>31</sup> There is a financial cost associated with travelling abroad for an assisted death, which can be in excess of £10,000 including the cost of travel and hotels. The process of arranging an assisted death overseas is extremely difficult and one which puts additional pressure on the person who is already suffering from a terminal illness. The requirement to be physically able to travel to Switzerland to have an assisted death means that people are ending their lives much sooner than they might otherwise choose to.

<sup>&</sup>lt;sup>32</sup> See the cases of Robert Hunter, Paul Brady, David Hainsworth. More recently, the cases of Ian Gordon and Suzanne Wilson are notable.

<sup>&</sup>lt;sup>33</sup> Murder attracts a mandatory life sentence on conviction. Criminal Procedure (Scotland) Act 1995, s 205.

such frequency. If the legal institutions are not prosecuting individuals, if they are treating convictions leniently and are allowing people to travel abroad to access/support assisted dying, then it would be better to allow assisted dying within a regulated framework. There is a risk to public trust in the legal institutions if the existing law proclaims an outright prohibition, but the consequences do not follow in practice.

People living with terminal illness have an increased likelihood of attempting to end their own life,<sup>34</sup> and many do, often alone and in traumatic circumstances.<sup>35</sup> Examples feature in a 2014 Dignity in Dying report and include Duncan McArthur who ended his own life, in October 2009, with medication he had stockpiled having been diagnosed with Motor Neurone Disease in 2006. His wife Susan was the subject of a police inquiry. There was no prosecution, but the inquiry meant a funeral could not take place until December 2009 and an inquest was not held until almost a year later. <sup>36</sup> More recently, Barbara Wall has shared the story of finding her father in his garage having taken his own life months after being diagnosed with terminal oesophageal cancer.<sup>37</sup>

As a country, we must do better by our dying citizens.

## 2.3 Public opinion

There is substantial and enduring public support for a change in the law on assisted dying, with numbers having risen since the last attempt to pass legislation at Holyrood in

<sup>36</sup> Dignity in Dying (2014), A Hidden Problem: Suicide by terminally ill people.

<sup>&</sup>lt;sup>34</sup> Goodwin, R D, Marusic, A J, Hoven, C W (2003) Suicide attempts in the United States: the role of physical illness. Social Science & Medicine Volume 56, Issue 8, April 2003, Pages 1783-1788. See: <a href="https://jamanetwork.com/journals/jamapsychiatry/fullarticle/2714596">https://jamanetwork.com/journals/jamapsychiatry/fullarticle/2714596</a>;

https://pubmed.ncbi.nlm.nih.gov/30613943/; https://www.nature.com/articles/s41467-018-08170-1; https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4346034/

<sup>&</sup>lt;sup>35</sup> See the story of Barbara Wall whose father was found in his garage having taken his own life months after being diagnosed with terminal oesophageal cancer at:

https://www.bmj.com/content/bmj/373/bmj.n1107.full.pdf; In February 2021, the Office for National Statistics (ONS) published data that suggested as many as 14.2% of suicides in England and Wales involved people who had been diagnosed with a potential serious health condition, but cautioned that this figure may involve double counting. The then Secretary of State for Health Matt Hancock commissioned the ONS to provide more data on this issue to inform debates around assisted dying and this is due to be published by the end of 2021. It is expected that this will include figures for Scotland. The indicative figures from the ONS mirrors what has been uncovered in other jurisdictions about the impact of the prohibition of assisted dying. In Victoria, Australia the Coroners Court advised a Parliamentary Inquiry that individuals with an irreversible decline in physical health were involved in 8.3% of suicides between 2009 and 2013. In Western Australia, individuals diagnosed with a terminal or debilitating physical condition accounted for 13.9% of suicides recorded between 2012 and 2017. See: <a href="https://questions-statements.parliament.uk/written-questions/detail/2021-02-04/hl13019">https://questions-statements.parliament.uk/written-questions/detail/2021-02-04/hl13019</a>

https://www.parliament.vic.gov.au/images/stories/committees/lsic/Submissions/Submission 1037 - Coroners\_Court\_of\_Victoria\_further\_submission.pdf

 $<sup>\</sup>frac{\text{https://www.parliament.wa.gov.au/parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/D885C273D79}{5E9484825821E000FC141/\$file/20171123+-+EOLC+-+Sub+537A+-}$ 

<sup>+</sup>State+Coroner+Western+Australia.pdf

<sup>&</sup>lt;sup>37</sup> BMJ 2021; Assisted dying: Hancock asks for more data on suicides of terminally ill people. See: <a href="https://www.bmj.com/content/bmj/373/bmj.n1107.full.pdf">https://www.bmj.com/content/bmj/373/bmj.n1107.full.pdf</a>

2015.<sup>38</sup> Support is balanced across political affiliation, gender, age and social status. Recent polling on this issue shows that 87% of the Scottish public back the introduction of an assisted dying law. <sup>39</sup>

Support for assisted dying is consistent across those who vote for the Scottish National Party (91%), Labour (84%), Conservatives (86%) and Liberal Democrats (87%).<sup>40</sup> 95% of Scots say that if their MSP was supportive of assisted dying it would make them feel more positively or have no effect on their feeling towards their MSP. <sup>41</sup>

The majority (82%) of religious people support a change in the law on assisted dying,<sup>42</sup> with a number of senior religious figures such as the former Archbishop of Canterbury Lord George Carey and Archbishop Desmond Tutu speaking out in support of assisted dying. <sup>43</sup> In Scotland, advocates for assisted dying include Richard Holloway, former Bishop of Edinburgh, Rev Scott McKenna of the Church of Scotland, and religious denominations such as the Scottish Unitarian Association and the Scottish Synod of the United Reformed Church. <sup>44</sup>

Polling has also shown that 88% of Scots living with a disability support assisted dying as a choice for terminally ill people.<sup>45</sup> More information on the views of religious people and those living with a disability is provided at section 4.1 of this document.

In 2020 the British Medical Association's first-ever survey of its members' views on assisted dying found that doctors support the choice of assisted dying. This exercise presents the largest ever survey of medical opinion on assisted dying in the UK<sup>46</sup> and ultimately led to the BMA dropping its opposition to assisted dying in a move to

<sup>&</sup>lt;sup>38</sup> 69% of voters in Scotland supported the Assisted Suicide (Scotland) Bill, according to a poll conducted by My Life, My Death, My Choice in January 2014.

<sup>&</sup>lt;sup>39</sup> Populus 2019, Dignity in Dying Scotland fieldwork 11-24<sup>th</sup> March 2019, at p.1 see: OmDignity-Scotland-Q1+2.wyp (yonderconsulting.com)

<sup>&</sup>lt;sup>40</sup> The Poll did not include data for those voting for the Scottish Green Party.

<sup>&</sup>lt;sup>41</sup> Populus 2019, Dignity in Dying Scotland fieldwork 11-24<sup>th</sup> March 2019, at p.1 see: <u>OmDignity-Scotland-Q1+2.wyp (yonderconsulting.com)</u> p.2.

<sup>&</sup>lt;sup>42</sup> Populus 2019, Dignity in Dying fieldwork 11-24<sup>th</sup> March 2019, at p.2 see: OmDignity-InclBoost-Q1+2.wyp (yonderconsulting.com) Populus interviewed 5,695 adults (aged 18+) in Great Britain online between 22 and 24 March 2019. Quotas and weights were used to ensure the sample was representative of the GB adult population. Interviews were conducted across Great Britain, with an increased sample level in Scotland, and the results were weighted to be representative of all British adults.

<sup>&</sup>lt;sup>43</sup> See: <u>George Carey: Former archbishop says Christians should support legal physician assisted dying - The BMJ and Archbishop Desmond Tutu 'wants right to assisted death' - BBC News</u>

<sup>&</sup>lt;sup>44</sup> See: <a href="https://blogs.bmj.com/bmj/2020/02/07/so-many-christians-support-legal-assisted-dying-not-because-they-see-life-as-unimportant-but-because-compassion-demands-it/">https://blogs.bmj.com/bmj/2020/02/07/so-many-christians-support-legal-assisted-dying-not-because-they-see-life-as-unimportant-but-because-compassion-demands-it/</a> and <a href="https://www.theguardian.com/society/2016/oct/07/desmond-tutu-assisted-dying-world-leaders-should-take-action">https://www.unitarian.org.uk/2021/06/10/dignity-in-dying/</a>

 $<sup>\</sup>frac{http://archive2021.parliament.scot/S4\_HealthandSportCommittee/Assisted\%20Suicide\%20Bill\%20submissions/ChurchandSocietyCommittee-UnitedReformedChurchSynodofScotlandASB279.pdf$ 

<sup>&</sup>lt;sup>45</sup> Populus 2019, Dignity in Dying Scotland fieldwork 11-24<sup>th</sup> March 2019, at p.1 see: <u>OmDignity-Scotland-Q1+2.wyp</u> (yonderconsulting.com) p.2.

<sup>&</sup>lt;sup>46</sup> BMA (2020) Physician-assisted dying survey at: <a href="https://www.bma.org.uk/advice-and-support/ethics/end-of-life/physician-assisted-dying/physician-assisted-dying-survey">https://www.bma.org.uk/advice-and-support/ethics/end-of-life/physician-assisted-dying/physician-assisted-dying-survey</a>

neutrality at its Annual Representative Meeting in September 2021.<sup>47</sup>Similar results have been found in surveys by the Royal College of Physicians<sup>48</sup> and Royal College of GPs,<sup>49</sup> demonstrating that the opposition to assisted dying that some doctors' groups have previously maintained is not sustainable.

The Royal College of Nursing, Royal College of Nursing Scotland, Royal College of Psychiatrists, and Royal Pharmaceutical Society all hold a neutral stance on assisted dying, with many other professional bodies not taking a formal position.<sup>50</sup> It is clear that both in this country and overseas, there has been a fundamental shift in opinion amongst healthcare professionals.

#### 2.4 Palliative care

Palliative care in the UK has been ranked number one in the world, with Scotland's services amongst the best in Europe.<sup>51</sup> Palliative and other End of Life care has greatly improved in recent decades and will continue to do so given the commitments made by the Scottish Government and those working within the sector.<sup>52</sup> However, there have been, are, and will continue to be limits to that care - some people experience severe emotional and physical suffering at the end of life despite receiving excellent palliative care.

Even if every dying person who needed it had access to high quality, specialist palliative care in Scotland, 591 people a year would still have unrelieved pain in the final three months of their life.<sup>53</sup> Figures from The Office of Health Economics (OHE) suggest that an estimated 11 Scots a week will experience no relief from their pain as they die, regardless of future investment in or improved access to specialist palliative care.<sup>54</sup> Some people experience other unavoidable symptoms such as severe nausea and vomiting, constipation, faecal vomiting, bowel fistulae, fungating wounds and terminal haemorrhages.

<sup>&</sup>lt;sup>47</sup> Politics.co.uk, BMA drops opposition to assisted dying, 14<sup>th</sup> September 2021, at: <u>BMA drops opposition</u> to assisted dying - Politics.co.uk

<sup>&</sup>lt;sup>48</sup> In March 2019, the Royal College of Physicians dropped its longstanding opposition to assisted dying in favour of neutrality following a member survey.

<sup>&</sup>lt;sup>49</sup> The Royal College of General Practitioners has maintained its opposition to assisted dying, despite a majority of GPs voting to support a change in the law or adopt a neutral stance.

<sup>&</sup>lt;sup>50</sup> General Medical Council, General Pharmaceutical Council, Royal College of Anaesthetists, Royal College of Obstetricians and Gynaecologists, Royal College of Paediatrics and Child Health, Royal College of Physicians of Edinburgh, Royal College of Surgeons of Edinburgh hold no stance on assisted dying.

<sup>&</sup>lt;sup>51</sup> A report for the Scottish Parliament by Professor David Clark: International comparisons in palliative care provision: what can the indicators tell us? Published 15th September 2015 SP Paper 784 9th Report, 2015 (Session 4) at para. 72 in ref to the Quality of Death Index.

<sup>&</sup>lt;sup>52</sup> Scottish Government, Palliative and end of life care: National Implementation Advisory Group, see: https://www.gov.scot/groups/palliative-and-end-of-life-care-national-implementation-advisory-group/

<sup>&</sup>lt;sup>53</sup> The Inescapable Truth About Dying in Scotland, Dignity in Dying Scotland, 2019.

<sup>&</sup>lt;sup>54</sup> The Inescapable Truth About Dying in Scotland, Dignity in Dying Scotland, 2019.

Many more people fear what they may be forced to endure at the end of their lives and feel denied control over their deaths. These feelings are forms of suffering in themselves and lead to a reduction in quality of life. Consequently, some dying people explore ways to hasten their deaths. These can be through travelling overseas for an assisted death, ending their lives behind closed doors, or by voluntarily stopping eating and drinking in an attempt to accelerate the dying process. Where assisted dying has been legalised, it has improved the quality and funding of palliative care. There are many examples.

First, assisted dying is associated with greater trust amongst patients and medical professionals. In countries where assisted dying is legal, trust in doctors is high. For example, research has shown that the country where doctors are most trusted is the Netherlands,<sup>55</sup> which has the longest acceptance of assisted dying as a legal procedure. In the UK, 93% of people say an assisted dying law would either increase or have no effect on their trust in doctors.<sup>56</sup>

This increased trust supports patients to make and communicate their decisions. Changing the law would allow a dying person to have honest, transparent conversations with their care team about their fears and wishes for the end of life and about other available palliative care options. Research demonstrates that assisted dying laws contribute to more open conversations and careful evaluation of end-of-life options, as well as more appropriate palliative care training of physicians and greater efforts to increase access to hospice care. <sup>57585960</sup> Oregon is considered to have amongst the best palliative care in the USA, and has had an assisted dying law in place for over 20 years.

In the US, approximately 90% of patients who request an assisted death are receiving hospice or palliative care.<sup>61</sup> This shows that palliative care access does not eliminate requests for assisted dying, nor does a request for assisted dying indicate a failure of palliative care. Rather, it shows that assisted dying is one of several options that can safely be made available to people at the end of life.

<sup>&</sup>lt;sup>55</sup> GfK Trust Index, 2008. GfK Custom Research reported that 88% of respondents in Belgium and 91% in the Netherlands trust their doctors.

<sup>&</sup>lt;sup>56</sup> Populus sample of 5000 people, details at Dignity in Dying (2015) Patients would trust doctors more if assisted dying was legal, at: Patients would trust doctors more if assisted dying was legal - Dignity in Dying

<sup>&</sup>lt;sup>57</sup> Legal regulation of physician assisted death – the latest report cards, New England Journal of Medicine 356:1911-1913, Quill TE, 2007.

<sup>&</sup>lt;sup>58</sup> Oregon physicians' attitudes about and experiences with end of life care since passage of the Oregon Death with Dignity Act, Journal of the American Medical Association 285:2363-2369, Ganzini L, Nelson HD, Lee MA et al, 2001.

<sup>&</sup>lt;sup>59</sup> Characteristics and proportion of dying Oregonians who personally consider physician assisted suicide, Journal of Clinical Ethics 15:111-118, Tolle SW, Tilden VR Drach LL, et al, 2004.

<sup>&</sup>lt;sup>60</sup> Oregon physicians' responses to requests for assisted suicide: a qualitative study, J. Palliat Med. Dobscha et al, 2004.

<sup>&</sup>lt;sup>61</sup> Oregon Health Authority Oregon's Death with Dignity Act and Washington State Department of Health Death with Dignity Act Reports consistently show this.

An objective of the Scottish Parliament Cross Party Group on End of Life Choices during the fifth session of the Parliament was to open up discussion on death and dying more generally in Scotland. A study from Oregon found that, while less than 0.5% of dying people opt for an assisted death, 1 in 50 had discussed it with their doctors, and 1 in 6 discussed it with their families. When assisted dying becomes legal, it leads to debate/discussion and an unprecedented interest in and planning around death. In California, which passed an assisted dying law in 2016, doctors now answer many questions about end-of-life care generally. A consequence of this is that more people actually make their wishes known and document them in instruments such as advance directives<sup>62</sup> and anticipatory care plans.

A second key way that assisted dying is supportive for palliative care is to do with resources. Legislation on assisted dying has been followed by large and continued investment in palliative care. This is evidenced in a number of jurisdictions. In 2015, the Palliative Care and Quality of Life Interdisciplinary Advisory Council (PCAC) was established in Oregon by Senate Bill 608. The legislation seeks to improve the lives of people who would benefit from palliative care and to facilitate better coordination of care.<sup>63</sup>

When the Australian State of Victoria passed assisted dying legislation, the government reviewed palliative care services in the area. As a result, an extra \$72 million has been provided in Victoria to increase palliative care beds and access to home-based palliative care. In Western Australia, where assisted dying legislation was passed in 2019, the government announced a further AU\$17.8 million for palliative care projects based on the recommendations of the Joint Select Committee Report on End of Life Choices.

A report commissioned by Palliative Care Australia which examined assisted dying around the world found "no evidence to suggest that palliative care sectors were adversely impacted by the introduction of legislation. If anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced." 66

Two years after assisted dying was legalised in Canada, the Minister of Health tabled a 'Framework on Palliative Care in Canada'. This framework provides a vision for

<sup>&</sup>lt;sup>62</sup> Los Angeles Times, There's an unforeseen benefit to California's physician-assisted death law, See: <a href="http://www.latimes.com/health/la-me-end-of-life-care-20170821-htmlstory.html">http://www.latimes.com/health/la-me-end-of-life-care-20170821-htmlstory.html</a>

<sup>&</sup>lt;sup>63</sup> Oregon Health Authority, Palliative Care and Quality of Life Interdisciplinary Advisory Council, SB 608, see: <a href="https://www.oregon.gov/oha/HPA/DSI/Pages/Palliative-Care-Advisory-Council.aspx">https://www.oregon.gov/oha/HPA/DSI/Pages/Palliative-Care-Advisory-Council.aspx</a>

<sup>&</sup>lt;sup>64</sup> Boost for Palliative Care Providers, 2017 see: <a href="https://www.jaclynsymes.com.au/media-releases/boost-for-palliative-care-providers-2/">https://www.premier.vic.gov.au/palliative-care-boost-support-terminally-ill-victorians</a>

<sup>&</sup>lt;sup>65</sup> Medical Forum (2019), Palliative Care A Human Right, at: <a href="https://mforum.com.au/palliative-care-a-human-right-vad-voluntary-assisted-dying/">https://mforum.com.au/palliative-care-a-human-right-vad-voluntary-assisted-dying/</a> see also: Government of Western Australia, Department of Health. Implementation Plan One 2019-2021 WA End-of-life and Palliative Care Strategy 2018-2028 Version: 12 June 2019.

<sup>&</sup>lt;sup>66</sup> Aspex Consulting on behalf of Palliative Care Australia (2018) Experience internationally of the legalisation of assisted dying on the palliative care sector.

palliative care in Canada and an implementation plan.<sup>67</sup> The government committed funding of \$6 billion over 10 years to improving palliative care with an additional \$184.6 million to improve home and palliative care for indigenous communities.<sup>68</sup>

## 2.5 Protecting vulnerable people

Where assisted dying is legal the evidence shows that such laws are safe and effective. The safeguards outlined at section 1.1 would act to ensure that vulnerable people are not adversely affected within the boundaries of the present proposal.

The people who tend to seek an assisted death are between 65 and 85, have a 'good education' and have cancer.<sup>69</sup> Studies have found that a request for an assisted death represents long-held philosophical beliefs among patients who highly value their independence<sup>70</sup> and autonomy.<sup>71</sup> Potentially vulnerable groups of people such as those of a lower socio-economic status or aged over 85 do not disproportionately use assisted dying laws.<sup>72</sup>

Under this bill proposal, two doctors would be required to independently assess the person making a request, including enquiring about their reasoning and motivations. This is an opportunity to make sure all options have been explored and to refer the person for psychiatric assessment if necessary. The person would be empowered to change their mind at any point.

Disability Rights Oregon has said that they have never "received a complaint that a person with disabilities was coerced or being coerced to make use of the Act". The Implementing a framework for legal reform would ensure the right checks and balances are in place for individuals and their families as well as for professionals involved in their care and would remove the current covert practices. Arguably, the current law in Scotland does not provide adequate protection to vulnerable people. Only a minority of cases are investigated when someone travels overseas for an assisted death. The fact that assisted dying overseas is tolerated without clear regulation means that we lack any clear safeguards for vulnerable people.

<sup>68</sup> Government of Canada (2019) see: <a href="https://www.canada.ca/en/health-canada/news/2019/05/minister-petitpas-taylor-announces-funding-to-help-strengthen-palliative-care.html">https://www.canada.ca/en/health-canada/news/2019/05/minister-petitpas-taylor-announces-funding-to-help-strengthen-palliative-care.html</a>

<sup>&</sup>lt;sup>67</sup> Framework on Palliative Care in Canada, Health Canada, 2018.

<sup>&</sup>lt;sup>69</sup> Oregon Death with Dignity Act, Data summary, 2020 and California End of Life Option Act, Data report 2018.

<sup>&</sup>lt;sup>70</sup> Medical Assistance in Dying (MAiD): A descriptive study from a Canadian tertiary care hospital, Am J Hosp Palliat Care, Selby D, 2019.

<sup>&</sup>lt;sup>71</sup> Colburn B, Autonomy, voluntariness and assisted dying, *Journal of Medical Ethics* 2020;46:316-319; Professor Colburn gave helpful advice and direction during a presentation to the CPG End of Life Choices during session five which has helped to inform this consultation.

<sup>&</sup>lt;sup>72</sup> Medical Assistance in Dying (MAiD): A descriptive study from a Canadian tertiary care hospital, Am J Hosp Palliat Care, Selby D, 2019.

<sup>&</sup>lt;sup>73</sup> Compassion and Choices (2019) at: <a href="https://compassionandchoices.org/letter-from-disability-rights-oregon-dro/">https://compassionandchoices.org/letter-from-disability-rights-oregon-dro/</a>

Under the current law, decisions that doctors can take that may hasten a person's death, such as withdrawing treatment or double effect,<sup>74</sup> involve far fewer safeguards and less oversight than would be present under an assisted dying law. Where some doctors are currently acting illegally to directly end a person's life at their request (voluntary euthanasia), there are no safeguards in place at all. The barrier that the current law creates does not stop people taking action to control the end of their lives but instead drives the practice behind closed doors. This means potentially vulnerable people cannot be and are not being protected.

In contrast, an assisted dying law would protect people by bringing these difficult decisions out into the open. It would introduce safeguards before a person could access an assisted death, and therefore provide both more protection and more choice than the current law allows.

#### 2.6 International context

Scotland has consistently demonstrated a willingness to learn from practice elsewhere<sup>75</sup> and this consultation has been informed by looking at how other devolved legislatures have acted.

Over 200 million people currently live in jurisdictions which have legalised some form of assisted dying including: the US States of Oregon, California, Hawaii, Washington Colorado, Vermont, Montana, New Jersey, New Mexico and Maine, Washington DC, the capital of the US, the Australian States of Victoria, Tasmania, Queensland and Western Australia, New Zealand, Canada, Belgium, the Netherlands, Luxembourg, Switzerland and Spain.

There is also significant activity in Ireland,<sup>76</sup> Austria,<sup>77</sup> Portugal,<sup>78</sup> France<sup>79</sup> and Jersey.<sup>80</sup> Assisted deaths in Oregon and California account for less than 1% of total deaths. Around 35% of people who are given the prescription choose not to use it. This shows

https://data.oireachtas.ie/ie/oireachtas/bill/2020/24/eng/initiated/b2420d.pdf

<sup>&</sup>lt;sup>74</sup> If the administration of medication results in the person's death but the intention was to relieve their symptoms of suffering, then this is permissible. G. H. Gordon, *Criminal Law* (1978), p 728.

<sup>&</sup>lt;sup>75</sup> Following the Assisted Suicide (Scotland) Bill falling in 2015, the Scottish Parliament Health and Sport Committee tasked Professor David Clark with producing a report titled 'International comparisons in palliative care provision: what can the indicators tell us?' 9th Report, 2015 (Session 4); also more recently, Finland for example, where the baby box programme originated and was subsequently implemented in Scotland.

<sup>&</sup>lt;sup>76</sup> Dying with Dignity Bill 2020 at:

<sup>&</sup>lt;sup>77</sup> Austria's top court decriminalises assisted dying

at: https://humanism.org.uk/2020/12/14/austrias-top-court-decriminalises-assisted-dying/

<sup>&</sup>lt;sup>78</sup> Portugal court deems physician assisted dying bill unconstitutional at:

https://www.jurist.org/news/2021/03/portugal-court-deems-physician-assisted-dying-bill-unconstitutional/

<sup>&</sup>lt;sup>79</sup> France Parliament debates bill to legalize assisted dying at: <a href="https://www.jurist.org/news/2021/04/france-parliament-debates-bill-to-legalize-assisted-dying/">https://www.jurist.org/news/2021/04/france-parliament-debates-bill-to-legalize-assisted-dying/</a>

<sup>&</sup>lt;sup>80</sup> Jersey Assisted Dying Citizens' Jury Recommendations – Initial Report (June 2021) at: https://www.gov.je/SiteCollectionDocuments/Caring%20and%20support/ID%20Jersey%20Assisted%20Dying%20Citizens%27%20Jury%20Recommendations%20-%20Initial%20Report%20FINAL.pdf

people want to live well for as long as possible, but with assisted dying as an 'insurance policy' if their suffering becomes unbearable.<sup>81</sup>

The UK Government recently asked the Office of National Statistics for more data on suicides by terminally ill people and the possible impact of the ban on assisted dying, noting that "anyone who believes in high quality public discourse would want to see an independent and impartial set of facts on which we can then have a discussion." One of the most robust considerations of assisted dying legislation is found in Canada, as a result of the *Carter v Canada* case. 83

Evidence received from Professors Battin, McLean, Bernheim, Deliens, Ganzini, Owens, Starks and Lewis in the *Carter* case showed that:

- there is no moral or ethical basis for the current blanket ban on assisted dying based on the sanctity of life
- persons can make a competent and rational choice to end their lives, and that whether their decision is a competent one and free of any undue pressure can be reliably assessed
- the empirical evidence from experts within the jurisdictions where the practice is legal, notably Oregon, the Netherlands and Belgium, is that there is no so-called 'slippery slope' in those jurisdictions, and that the opposite is the case
- there is no appreciable risk to vulnerable groups from a carefully controlled legal regime
- legalisation improves access to palliative care rather than the contrary
- patient confidence in the medical profession is enhanced not undermined in permissive jurisdictions
- the legal safeguards, both substantive and procedural, in those jurisdictions have become enhanced, not eroded, over time.<sup>84</sup>

There is evidence as to the harm that is caused by the current prohibition on assisted dying in the United Kingdom, including the scale of the practice of euthanasia notwithstanding that the practice is illegal,<sup>85</sup> and that there is a risk of persons taking their lives earlier than they would otherwise wish. More generally the current prohibition undermines individual autonomy, including for those who do not currently want to end their lives. A change in the law would increase everyone's capacity to make voluntary choices about their care.<sup>86</sup>

<sup>&</sup>lt;sup>81</sup> Ganzini L, Beer TM, Brouns M et al, 2006, Interest in physician-assisted suicide among Oregon cancer patients, Journal of Clinical Ethics 17:27-38,

<sup>&</sup>lt;sup>82</sup> Dignity in Dying (2021) Cross-Party Group on End-of-Life Choice welcomes health secretary's request for more data on suicides by terminally ill people and impact of assisted dying ban. See: <a href="https://www.dignityindying.org.uk/news/cross-party-group-on-end-of-life-choice-welcomes-health-secretarys-request-for-more-data-on-suicides-by-terminally-ill-people-and-impact-of-assisted-dying-ban/">https://www.dignityindying.org.uk/news/cross-party-group-on-end-of-life-choice-welcomes-health-secretarys-request-for-more-data-on-suicides-by-terminally-ill-people-and-impact-of-assisted-dying-ban/">https://www.dignityindying.org.uk/news/cross-party-group-on-end-of-life-choice-welcomes-health-secretary's request for more data on suicides by terminally ill people and impact of assisted dying ban. See: <a href="https://www.dignityindying.org.uk/news/cross-party-group-on-end-of-life-choice-welcomes-health-secretarys-request-for-more-data-on-suicides-by-terminally-ill-people-and-impact-of-assisted-dying-ban/">https://www.dignityindying.org.uk/news/cross-party-group-on-end-of-life-choice-welcomes-health-secretarys-request-for-more-data-on-suicides-by-terminally-ill-people-and-impact-of-assisted-dying-ban/">https://www.dignityindying.org.uk/news/cross-party-group-on-end-of-life-choice-welcomes-health-secretarys-request-for-more-data-on-suicides-by-terminally-ill-people-and-impact-of-assisted-dying-ban/">https://www.dignityindying.org.uk/news/cross-party-group-on-end-of-life-choice-welcomes-health-secretarys-request-for-more-data-on-suicides-by-terminally-ill-people-and-impact-of-assisted-dying-ban/">https://www.dignityindying.org.uk/news/cross-party-group-on-end-of-life-choice-welcomes-health-secretarys-request-for-more-data-on-suicides-by-terminally-ill-people-and-impact-of-assisted-dying-ban/">https://www.dignityindying.org.uk/news/cross-party-group-on-end-of-life-choice-welcomes-health-secretarys-request-for-more-data-on-suicides-by-terminally-ill-people-and-impact-of-assisted-dying-by-terminally-ill-people-and-impac

<sup>&</sup>lt;sup>84</sup> Extract taken from skeleton argument for Omid T v Secretary of State case 7,8 March 2018.

<sup>85</sup> Euthanasia: doctors aid 3,000 deaths | Health | The Guardian

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<sup>&</sup>lt;sup>86</sup> Colburn B, Autonomy, voluntariness and assisted dying, *Journal of Medical Ethics* 2020;46:316-319

There have also been extensive consultations abroad which provide significant evidence and research on this topic, including the Ministerial Expert Panel on Voluntary Assisted Dying in Western Australia, a Ministerial Advisory Panel and subsequent Inquiry into End of Life Choices in Victoria, Australia and an Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying in Queensland, Australia.

Scotland will not be taking a leap into the unknown. We now have over 20 years' worth of data and research to confidently allow us to legislate for the majority of our citizens who support this choice.

## 3 Detail of the proposed Bill

It is important to emphasise that the information below is only an outline of what is being proposed and consulted on, it is not a Bill. We hope that, via this consultation process, we will receive suggestions and comments which will help us to refine and improve our proposals, which will then be reflected in the draft Bill when it is produced.

## 3.1 The process

#### Step 1: Declaration (request for an assisted death)

The person who has a terminal illness reaches a clear, settled and voluntary intention to end their life, and signs a declaration in the presence of two independent witnesses. The declaration must be signed by a registered medical doctor from whom the person has requested assistance to end their life (the attending doctor) and another registered medical doctor (independent doctor). Before signing the person's declaration, the attending and independent doctor must separately examine the person and the person's medical records and, each acting independently of the other, be satisfied that the person is terminally ill, has the capacity to make such a decision<sup>87</sup>, and has reached a clear and settled intention on an informed basis, without coercion or duress. If the attending or independent doctor has doubts as to the person's capacity to make a decision, the doctor must refer the person to an appropriate specialist, such as a psychologist, and take account of their opinion of the person's capacity.

The attending doctor must explain any feasible alternatives, which will normally include pain relief, hospice support and other palliative care packages that are available to the patient. The attending doctor must also discuss the reasons for wanting an assisted death with the patient. The attending doctor must then complete a declaration and review a questionnaire form with a view to submitting this to the reporting body after the death.

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<sup>87</sup> Adults with Incapacity (Scotland) Act 2000 s. 1.

#### Step 2: Reflection period

A time period must pass before the attending doctor prescribes medication for that person to end their life. The suggested period would be 14 days after the attending doctor completes the declaration, though if the attending doctor and independent doctor agree that the person's death is reasonably expected to occur within 30 days, the reflection period can be shortened. We welcome views on this aspect of the process in consideration of the varying approaches taken by other jurisdictions.<sup>88</sup>

## Step 3: Prescribing/delivering

The attending doctor of a person who has made a valid declaration may prescribe medication for the person. The medication(s) prescribed must be delivered to the person by a registered healthcare practitioner (HCP) and only after the HCP has confirmed that the person has not revoked or wishes to revoke their declaration. In this context, a registered healthcare practitioner includes nurse practitioners.<sup>89</sup> The HCP present may then prepare the medicine for self-administration by that person. The HCP must be present when the person takes the medicine.<sup>90</sup>

The attending HCP should then complete the follow-up form.

The declaration, questionnaire and follow-up form should then be sent to the reporting body no later than one calendar month from the person's death. The reporting body would periodically present summary data that they receive.

Death certificates are public documents, and in the interests of privacy, the primary cause of death would be noted as the underlying illness from which the person died. It is envisaged that the paperwork and the potential creation of a reporting and oversight body would satisfy public health awareness, research and resource allocation requirements.

<sup>&</sup>lt;sup>88</sup> For example, New Mexico have a 48-hour waiting period which can be waived if death is imminent (section 24-7C-5) whilst in Oregon patients are exempt from any waiting period that exceeds their life expectancy i.e., patients with less than 15 days to live are exempt from the 15-day waiting period between the first and second oral requests for medication. Patients with less than 48 hours to live are exempt from the 48-hour waiting period between the patient's written request and the writing of the prescription.

<sup>&</sup>lt;sup>89</sup> This decision has been taken after considering international evidence from jurisdictions where nurse practitioners participate in the process. We recognise that over the past decades custom and practice in healthcare has seen nurse practitioners take on increasing responsibilities and that the divide between doctors and nurse practitioners has narrowed. Furthermore, given the geography of Scotland, we believe that it will address any issues with access re rural communities. We are very keen to hear the views of nurse practitioners and others on this matter.

<sup>&</sup>lt;sup>90</sup> This is to ensure that it is ingested safely and properly.

## 3.2 Prognosis and capacity

In Scotland, a person is terminally ill if a registered medical practitioner has diagnosed them as having a progressive disease, which can reasonably be expected to cause their death. <sup>91</sup> Terminal illness is defined, for the purposes of providing social security, as that suffered by those who are deemed by doctors as 'unable to recover', regardless of the time they have left to live. This is Scottish Government Policy, supported by members of the Scottish Parliament. It was thoroughly considered and decided upon during the passing of the Social Security (Scotland) Act 2018. Under the previous system, a claimant was not deemed to be suffering from a terminal illness unless medics considered that they had six months or less to live. <sup>92</sup>

As this definition of terminal illness, based purely on clinical judgment, is the definition agreed by both the Scottish Parliament and the Scottish Government we would intend using it in the proposed Bill. As such we have not included a rigid prognosis timeframe on which to determine eligibility.

Eligibility will still be certified by a registered medical doctor using professional judgement on a case-by-case basis.

An assisted dying law would require the attending and independent doctor to:

- Assess whether the person seeking an assisted death has the capacity to make the decision
- Assess whether the person is doing so voluntarily
- Consider and affirm that the person has a diagnosis of a terminal illness.

Doctors are suited to doing this.<sup>93</sup> For example, when someone chooses to refuse medical treatment that will result in their death, doctors are required to make sure that the person has capacity and is not being coerced. The British Medical Association and the Association for Palliative Medicine provide statements on this.<sup>94</sup>

## 3.3 Conscience

It is important that doctors and other healthcare professionals are able to conscientiously object (CO) to supporting their patients through an assisted dying request. It is recognised, however, that if the Bill becomes law it would be the patient's

<sup>&</sup>lt;sup>91</sup> Scottish Government, Social Security Policy, Terminal Illness <a href="https://www.gov.scot/policies/social-security/terminal-illness/">https://www.gov.scot/policies/social-security/terminal-illness/</a> Whilst this is a specific policy adopted for a specific purpose, it is generally agreed as a reasonable definition and has been adopted for the purposes of this consultation.
<sup>92</sup> Scottish Government (2019) Social Security. <a href="https://www.gov.scot/policies/social-security/terminal-illness/">https://www.gov.scot/policies/social-security/terminal-illness/</a>

<sup>&</sup>lt;sup>93</sup> Although doctors are best placed to perform this role, as with all aspects of this process, additional training and ongoing support will be instituted.

<sup>&</sup>lt;sup>94</sup> See: <a href="https://www.bma.org.uk/media/1849/bma-mental-capacity-act-toolkit-2016.pdf">https://www.bma.org.uk/media/1849/bma-mental-capacity-act-toolkit-2016.pdf</a> and <a href="https://apmonline.org/wp-content/uploads/2016/03/Guidance-with-logos-updated-210316.pdf">https://apmonline.org/wp-content/uploads/2016/03/Guidance-with-logos-updated-210316.pdf</a>

legal right to request assistance, and a referral to another consenting doctor should be made if the initial doctor declined to assist the patient because of their personal beliefs.

As with doctors, any healthcare professional, including pharmacists and others, would not be obliged to participate. This represents current practice in other areas, where a conscientious objection may be present, such as termination of pregnancy or the withdrawal of life-sustaining treatment.

Guidance from the General Medical Council<sup>95</sup> on personal beliefs and medical practice states that doctors may practise medicine in accordance with their beliefs, provided that they act in accordance with relevant legislation and:

- do not treat patients unfairly
- do not deny patients access to appropriate medical treatment or services
- do not cause patients distress.

The policy intent is that no person will be obliged to participate in the assisted dying process. The full range of options to achieve this will be explored, including the use of a protection for conscience provision / 'opt out' clause within the confines of legislative competence constrains.

A register of HCPs and staff whose personal ethics do permit participation will be developed with consideration given to who could access this register.

# 4 Implications of the proposed Bill

## 4.1 Equalities

Having considered the provisions of the Equality Act 2010, the proposal is deemed as relevant to several of the identified characteristics protected by law, namely;

#### Age

Healthcare practitioners are increasingly encountering older adults expressing wishes to end their life. 96 Research and data collected from permissive jurisdictions 97 shows that assisted dying is likely to be used disproportionately by older people, as these are the people most likely to be diagnosed with a qualifying terminal illness. However, the Bill makes access to assisted dying equally available to adults (over-16s) of any age.

<sup>&</sup>lt;sup>95</sup> General Medical Practice, Personal beliefs and medical practice, at: <a href="https://www.gmc-uk.org/ethical-guidance-for-doctors/personal-beliefs-and-medical-practice/personal-beliefs-and-medical-practice/personal-beliefs-and-medical-practice">https://www.gmc-uk.org/ethical-guidance-for-doctors/personal-beliefs-and-medical-practice/personal-beliefs-and-medical-practice</a>. Guidance has also been produced by the British Medical Association, Royal College or Nursing and others.

<sup>&</sup>lt;sup>96</sup> M Balasubramaniam. 2018. "Rational Suicide in Elderly Adults A Clinician's Perspective" J Am Geriatr Soc;66(5):998-1001 https://www.ncbi.nlm.nih.gov/pubmed/29500824

<sup>&</sup>lt;sup>97</sup> Oregon Death with Dignity Act, Data summary, 2020; California End of Life Option Act, Data report 2018.

#### **Disability**

88% of Scots living with disability support assisted dying as a choice for terminally ill people. 98 We recognise that there is a range of views from disabled people on this matter, and we are very keen to engage with members of the disabled community when building in appropriate safeguards to take the lived experience of vulnerability into proper account.

There are two key points to bear in mind here. The first is the overarching and simplest safeguard: people would not qualify under this proposal's criteria by having a disability alone. The choice would only be available if they also have a terminal illness. Second, as noted earlier, the status quo has no protections; building a regulatory framework better protects everyone (including disabled people) because end-of-life conversations can take place out in the open, with explicit safeguards to protect the vulnerable. Professor Ben Colburn (University of Glasgow, 2021) assessed the hypothesis that the disabled community would be negatively affected by an assisted dying law. Colburn systematically studied reviews over the past ten years, capturing all published data (since legalisation in each jurisdiction) on the uptake of assisted dying amongst vulnerable people, including people with disabilities. The conclusion was that in no jurisdiction was there evidence that vulnerable people were subject to abuse, 99 and the hypothesis that people with disabilities might be disproportionately impacted was not borne out. Colburn states that this conclusion is reinforced if we look directly at the empirical data, "These findings - that there is no evidence that assisted dying laws have a disproportionate effect on people with disabilities – are echoed in all empirical studies which examine the question."100

A recent survey of disability rights organisations in the UK indicated various stances and policies on assisted dying. Of 140 such organisations surveyed, a substantial majority remain silent (84%) or explicitly endorse neutrality (4%). Only 4% explicitly oppose it. For those who remain neutral, the position of Disability Rights UK is representative: "This is a complex issue on which people hold different, passionately held views. Disability Rights UK respects those different views." As Tom Shakespeare observes, "notwithstanding the blanket opposition of "their" organizations, people with disabilities

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<sup>&</sup>lt;sup>98</sup> Populus 2019, Dignity in Dying Scotland fieldwork 11-24<sup>th</sup> March 2019, at p.1 see: <u>OmDignity-Scotland-</u>Q1+2.wyp (yonderconsulting.com) p.2.

<sup>&</sup>lt;sup>99</sup> Wayne Sumner notes that 'many people in the disability community find this stereotyping to be itself demeaning and patronizing, complaining that it feeds rather than starves social prejudices'. Even some opponents of assisted dying accept that this line of argument might involve a 'paternalistic over-emphasis of the vulnerability of persons with disabilities'.

<sup>&</sup>lt;sup>100</sup> Colburn, B., Assisted Dying and Disability (2021): <u>Policy Briefing: Disability and Assisted Dying Laws</u> - Policy Scotland

<sup>&</sup>lt;sup>101</sup> Box G, Chambaere K. Views of disability rights organisations on assisted dying legislation in England, Wales and Scotland: an analysis of position statements. J Med Ethics. 2021 Jan 5.

<sup>&</sup>lt;sup>102</sup> Disability Rights UK. 2015. 'Our position on the proposed Assisted Dying Bill'.

https://www.disabilityrightsuk.org/news/2015/september/our-position-proposed-assisted-dying-bill (accessed 30 July 2021).

in the United Kingdom do not oppose assisted dying with one voice... at a minimum the views of the wider community are more mixed than the views of their leaders." <sup>103</sup>

We recognise that people with disabilities continue to face social stigma, inequalities in access to public life, and a lack of adequate support for basic social, economic, and civic participation. Those problems need urgent attention, and legalising assisted dying alone will not deal with broader problems to do with funding and support for social care and disability support. However, it is possible to advocate for greater resourcing for those provisions whilst also increasing the choices available at the end of life.

Marquardt (2021), appealing to the UN Convention on the Rights of Disabled People, has said that: "people with disabilities deserve access to [assisted dying]. The UNCRPD warns against undue influence in the exercising of legal rights and urges appropriate and effective safeguards against abuse, but it still demands equal access ... The social determinants of health that amplify unequal outcomes will not be resolved by restricting harm-reducing services. The prolongation of suffering impacts not only the individual but their family as well." 104

Colburn concludes that it would be a mistake to "oppose legalising assisted dying until those wider problems are fixed.<sup>105</sup> For one thing, changes in the law to allow assisted dying, perhaps precisely by drawing attention to that wider context, can go hand in hand with developments that improve other aspects of end-of-life care. It bears repeating that there is no tension between assisted dying and a well-supported palliative care regime for patients who do not seek to end their lives. For another, the opposing stance is in danger of ignoring the ongoing costs of the status quo."<sup>106</sup> As Professor Riddle<sup>107</sup> puts it, "…the experiences relayed by people with disabilities and the words of caution expressed are valuable in assessing the system to reduce or eliminate the possibilities of harm, but not to eliminate or prevent the system itself."<sup>108</sup>

#### Gender

Research has shown that the lack of choice at the end of life disproportionately and detrimentally affects women who continue to be the primary care givers at the end of

<sup>&</sup>lt;sup>103</sup> Shakespeare T. 2016. 'Just What Is The Disability Perspective on Disability?', Hastings Center Report 46: 31-32.

<sup>&</sup>lt;sup>104</sup> Marquardt DS. 2021. 'Medical Assistance in Dying and Disability Rights' in Social Work & PolicyStudies4: 1–9.

<sup>&</sup>lt;sup>105</sup> Stainton T. 2019. 'Disability, vulnerability and assisted death: commentary on Tuffrey-Wijne, Curfs, Finlay and Hollins', BMC Medical Ethics 20: 89.

<sup>&</sup>lt;sup>106</sup> Colburn, B., Assisted Dying and Disability (2021): <u>Policy Briefing: Disability and Assisted Dying Laws</u> - Policy Scotland

<sup>&</sup>lt;sup>107</sup> Specialist in applied ethics, especially philosophical issues arising from the experience of disability.

<sup>&</sup>lt;sup>108</sup> Riddle CA. 2017. 'Assisted Dying & Disability', Bioethics 31: 484-9.

life.<sup>109</sup> Evidence from permissive jurisdictions suggests that similar numbers of men and women avail themselves of the legislation.<sup>110</sup>

#### Race

Data shows that the rates of use of assisted dying are much higher for people identifying as white. Over almost twenty years, only three percent of people who died after receiving assisted dying in Oregon identify as any race other than white.<sup>111</sup>

Explanations for racial and ethnic variability in use of assisted dying fall into three broad areas: cultural, structural, and interactional explanations. In September 2019, the Cross Party Group on End of Life Choices heard from Dr Mehrunisha Suleman, University of Cambridge about the intergenerational differences within the Muslim community which may impact end of life choices. We are keen to hear the views of others from within different ethnic minority communities.

#### Religion or belief

There is a mixed position with regard to views on assisted dying amongst Scottish faith and belief communities. Some faith and belief bodies, such as Humanists and Unitarians, actively support changing the law and are active in campaigning to change it. Other groups such as the Catholic Church and the Church of Scotland have opposed previous attempts to legislate in this area.

As noted at 3.3, there is evidence that people support assisted dying across the membership of different faith and belief groups, or being part of none. It is important to note that the freedom of religion and belief protects individuals but not institutions, and protects individuals with non-religious convictions as equally as those with religious beliefs.

It is understood that for some individuals, their beliefs would mean that they would not wish to be part of an assisted death process. As noted at 4.3, it is a foremost priority of this proposal to explore, within the realms of Scottish Parliament competency, how those in the medical profession who wished not to be involved can ascertain their article 9 rights of freedom of religion or belief, i.e. to opt-out based on conscience. It is also known that for other individuals the current prohibition on the choice of assisted dying restricts access to a service that would coincide with their beliefs that it is compassionate, moral, and ethical to provide relief from a potential bad death for those

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Dying in Scotland: A Feminist Issue at: https://features.dignityindying.org.uk/dying-in-scotland/For example, in Oregon, between 1998-2018 the split was 52.2% male, 47.8% female. The data groups 'sex' as male and female. See:

https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx

<sup>&</sup>lt;sup>111</sup> OHPD, 2016. Although California is much more racially and ethnically diverse than Oregon, the numbers there still show that most people who use assisted dying are white: 89.5% of the Californians using the End of Life Option Act (EOLOA) were identified as white (CDPH, 2017).

<sup>&</sup>lt;sup>112</sup> Cain CL, McCleskey S. Expanded definitions of the 'good death'? Race, ethnicity and medical aid in dying. *Sociol Health Illn*. 2019;41(6):1175-1191. doi:10.1111/1467-9566.12903.

who would choose that option. As the proposals herein are based on a scheme of opt-in for patients, there is no manifest challenge to individuals whose beliefs would preclude them from making such a choice. This is consistent with the approach which is usually taken when individuals have diverse religious and moral convictions.<sup>113</sup>

The above characteristics have been identified as being particularly affected, but views on all protected characteristics are welcomed.

## 4.2 Sustainability

Well-being and future proofing are central parts of sustainable development and this proposed Bill should both improve the well-being of people with terminal illness and lead to positive outcomes for patients, families and Scottish society as a whole. Families throughout Scotland have articulated the trauma that they have had to experience due to a lack of choice at the end of life.<sup>114</sup>

Case law has shown us that citizens endure considerable physical/psychological suffering and/or loss of dignity because of a lack of legal facilitation, 115 experiencing heightened anxiety as a result of their ongoing distress, reinforced by the anticipation of an unpleasant death. 116 This distress extends to those caring for them, who have to witness their loved ones suffering and being denied an end to life which aligns with their wishes and values.

The fear that the terminally ill express is often not of dying itself but the way in which they will die. They dread a 'bad' death involving loss of autonomy, pain and indignity. Conversely in jurisdictions that have legalised assisted dying, the 'emotional insurance'<sup>117</sup> of having the choice is well documented, with people living longer, with reduced anxiety and existential symptoms. Around 35 per cent of people in Oregon, who go through the process of being approved to receive medication to end their lives, do not use it.<sup>118</sup> Once they have the option to relieve their suffering, many choose to continue living and go on to die of natural causes.<sup>119</sup> At present, Scots who would welcome having the choice must endure the fear, anxiety, and suffering that

<sup>&</sup>lt;sup>113</sup> Rawls 1993 and Dworkin 1994.

<sup>&</sup>lt;sup>114</sup> See Heather Black's family story at: <a href="https://www.scotsman.com/news/politics/insight-daughters-demand-right-die-name-their-campaigning-mother-2890577">https://www.thetimes.co.uk/article/grandmothers-suffering-prompts-assisted-dying-appeal-7v72l672q</a>

<sup>&</sup>lt;u>nttps://www.tnetimes.co.uk/article/grandmotners-suffering-prompts-assisted-dying-appeal-7772l672q</u>
Leighanne Sangster Baird and Corrie Black at:

https://www.thetimes.co.uk/article/dying-treated-worse-than-animals-mhb08twrv and

Liz Wilson at: <a href="https://www.dailyrecord.co.uk/news/scottish-news/he-just-wanted-pain-stop-14210219">https://www.dailyrecord.co.uk/news/scottish-news/he-just-wanted-pain-stop-14210219</a>

115 Pretty, Purdy, Nicklinson etc.

<sup>&</sup>lt;sup>116</sup> Sue Westwood, 'Older Lesbians, Gay Men and the 'Right to Die' Debate…', Social and Legal Studies. 2017.

<sup>&</sup>lt;sup>117</sup> R. Huxtable & M. Möller. 'Setting a Principled Boundary'? Euthanasia as a Response to 'Life Fatigue'. Bioethics 2007; 21(3): 117–126. At page 474.

<sup>&</sup>lt;sup>118</sup> Oregon Health Authority. Annual reports.

<sup>&</sup>lt;sup>119</sup> Ganzini L, Beer TM, Brouns M et al, 2006, Interest in physician-assisted suicide among Oregon cancer patients, Journal of Clinical Ethics 17:27-38.

accompanies a terminal diagnosis. This could be alleviated by extending their options to include assisted dying. 120 As such this Bill should make a positive contribution to the sustainable development of Scottish society in the years ahead and would build towards a more compassionate Scotland.

A fundamental aspect of sustainable development is ensuring that economic, cultural and political systems do not favour some people while harming others. We believe that introducing a law would redress the inequalities in the current position outlined at 2.2 (Consequences of the current position) and ensure that all persons have equal access to this choice. There is a financial cost associated with travelling abroad for an assisted death, which can be in excess of £10,000 including the cost of travel and hotels. The process of arranging an assisted death overseas is extremely distressing and one which puts additional pressure on the person who is already suffering from a terminal illness. The requirement to be physically able to travel abroad to have an assisted death means that people are ending their lives much sooner than they might otherwise choose to, thus denying them precious time with their loved ones.

Previous attempts noted that by providing a mechanism for assisted dying in Scotland, the Bill will particularly increase choice for those on lower incomes, given that the only current equivalent (travel to an organisation such as Dignitas in Switzerland) is expensive and so affordable only to the better-off. Even for those who can afford it, there are disadvantages – many prefer to die at home rather than in an unfamiliar place, and the friends or relatives who accompany them face the possibility of prosecution or other legal action on their return.

The member is pursuing this Bill proposal in the belief that the current law does not fully respect people's rights to control the timing and manner of their own deaths, and their right to a dignified death. To that extent, in the member's view, the Bill proposal would enhance human rights. The Bill proposal has implications for human rights under ECHR – particularly Article 2 (right to life) and Article 8 (right to respect for private and family life) and Article 14 (with Article 2 or 8) (protection from discrimination). The proposal seeks to meet a range of United Nations Sustainable Development Goals (SDG)50, including— SDG 3 Good health and well-being; SDG 5 Gender Equality; SDG 10 Reduced inequalities; and; SDG 16 Peace, Justice and Strong Institutions.

While the Bill proposal applies in the same way throughout Scotland, assisted dying may in practice be harder to obtain for people living in small and remote communities, including island communities – particularly as travelling is likely to be particularly difficult for people with a terminal illness. The process requires the direct involvement of a number of other people to carry out certain functions, for example the two independent doctor assessments at stage 1. It may be harder for a person living in a small and

<sup>&</sup>lt;sup>120</sup> Colburn B, Autonomy, voluntariness and assisted dying, *Journal of Medical Ethics* 2020;**46:**316-319.

<sup>&</sup>lt;sup>121</sup> It should be noted that the organisations providing this assistance operate as not for profit and do, on occasion, support people with fee waivers etc.

<sup>&</sup>lt;sup>122</sup> Assisted Suicide (Scotland) Bill Policy Memorandum at: <a href="https://archive2021.parliament.scot/S4\_Bills/Assisted%20Suicide/b40s4-introd-pm.pdf">https://archive2021.parliament.scot/S4\_Bills/Assisted%20Suicide/b40s4-introd-pm.pdf</a>

remote community to identify individuals who are able to attend at the relevant time and place. It may also be more difficult for someone living in such a location to gain access to an alternative doctor if the only local doctor declines to assist on grounds of conscience. The member acknowledges these difficulties and is keen to hear views on how this can be mitigated. 123

Relationships and trust between doctors and patients will likely benefit as noted at section 2.4 of this consultation. Empowering patients to take control over their own dying signals a shift away from paternalism to more positive and autonomous patient-centred decision making.

Overall, it is suggested that the proposed Bill can support sustainable development issues by increasing wellbeing, equity and access to justice.

## 4.3 Resource implications

Evidence from countries where assisted dying is legalised suggests that the implementation of assisted dying will likely remain at least cost neutral. There are implications for the NHS through the role conferred on registered healthcare professionals and other stakeholders such as pharmacists.

Should the Scottish Government and related services provide resources and public information to raise awareness of the legislation, as would be expected, there would be cost implications.

Additional training and support to healthcare practitioners and others may also require additional resources to help support the transition to any new arrangements.

Depending on the approach taken, the reporting body provisions would incur additional cost. This might be mitigated to an extent if responsibility for reporting is attributed to an existing body such as Public Health Scotland or the Office of the Public Guardian.

Potential costs could therefore include:

Scotland-wide information campaign to raise awareness of the change in the law

<sup>&</sup>lt;sup>123</sup> Research from permissive jurisdictions shows that assessments can be undertaken via video link with the doctor and the patient in exceptional circumstances. Indeed, this has become more common practice for healthcare more generally since the Covid-19 pandemic forced us all into new ways of working.

<sup>124</sup> A cost analysis of assisted dying in Canada was undertaken in 2017 and concluded that "Medical assistance in dying could reduce annual health care spending across Canada by between \$34.7 million and \$138.8 million, exceeding the \$1.5–\$14.8 million in direct costs associated with its implementation. In sensitivity analyses, it was noted that even if the potential savings are overestimated and costs underestimated, the implementation of medical assistance in dying will likely remain at least cost neutral. see: Trachtenberg AJ, Manns B. Cost analysis of medical assistance in dying in Canada. *CMAJ*. 2017;189(3):E101-E105. doi:10.1503/cmaj.160650.

- Educational materials, training and support aimed at healthcare practitioners, patients, the public and other stakeholders
- Additional costs associated with the reporting and monitoring body as regards
  the data collection aspects of the proposed bill, particularly if a new body was to
  be set up
- Costs on governing bodies for registered healthcare practitioners and pharmacists etc. in revising codes of conduct etc.

Any additional costs borne should not be considered in isolation, they must also be considered alongside the benefits that having this choice provides to people who would choose it.

The current extent to which assisted dying is under-reported is not fully known, but there would likely be a saving regarding police and COPFS resource implications as people would go through the assisted dying process, rather than taking matters into their own hands. Thus, savings would be borne out by a reduced need for police investigations and court proceedings after the fact.

#### 4.4 Data collection

An initial screening exercise has been carried out which reflects that a number of elements of the proposals relate to the processing of personal data. These include that:

- the process of requesting an assisted death requires the terminally ill person to sign a declaration in the presence of two independent witnesses. That declaration must be signed by a registered medical doctor practitioner from whom the person has requested assistance to end their life and another registered medical doctor;
- the attending doctor must then complete a declaration and review a
  questionnaire form with a view to submitting this to a reporting body (to be
  determined) after the death;
- the health care professional that administers the medicine to assist death then completes a "follow-up form". The declaration, questionnaire and follow-up form should then be sent to the reporting body no later than one calendar month from the person's death. The reporting body would periodically present summary data that they receive;
- the part of the proposal, relating to conscience (i.e. a health care professional not being required to be involved in an assisted death as a matter of objection) states that a register of Health Care Professionals and staff whose personal ethics do permit participation will be developed with consideration given to who could access this register.

Therefore, this consultation will be sent to the ICO for comment and as the proposal develops further into a final proposal and a bill its provisions will be closely monitored to

ensure any impact on the processing of personal data is closely monitored and scrutinised.	

# Questions

# About you

(Note: Information entered in this "About You" section may be published with your response (unless it is "not for publication"), except where indicated in **bold**.)

1.	Are you responding as:
	<ul><li>an individual – in which case go to Q2A</li><li>on behalf of an organisation? – in which case go to Q2B</li></ul>
2A.	Which of the following best describes you? (If you are a professional or academic, but not in a subject relevant to the consultation, please choose "Member of the public".)
	<ul> <li>Politician (MSP/MP/peer/MEP/Councillor)</li> <li>Professional with experience in a relevant subject</li> <li>Academic with expertise in a relevant subject</li> <li>Member of the public</li> </ul>
	Optional: You may wish to explain briefly what expertise or experience you have that is relevant to the subject-matter of the consultation:
2B.	Please select the category which best describes your organisation:
	<ul><li>Public sector body (Scottish/UK Government or agency, local authority, NDPB)</li></ul>
	Commercial organisation (company, business)
	<ul> <li>Representative organisation (trade union, professional association)</li> <li>Third sector (charitable, campaigning, social enterprise, voluntary, non-profit)</li> </ul>
	Other (e.g. clubs, local groups, groups of individuals, etc.)
	Optional: You may wish to explain briefly what the organisation does, its experience and expertise in the subject-matter of the consultation, and how the view expressed in the response was arrived at (e.g. whether it is the view of particular office-holders or has been approved by the membership as a whole).

3.	Please	choose one of the following:
	_	am content for this response to be published and attributed to me or my organisation
		I would like this response to be published anonymously would like this response to be considered, but not published ("not for publication")
	•	have requested anonymity or asked for your response not to be published, give a reason. (Note: your reason will not be published.)
4.	will no	provide your name or the name of your organisation. (Note: The name to be published if you have asked for the response to be anonymous to for publication".)
	Name	e:
	your res	provide a way in which we can contact you if there are queries regarding sponse. Email is preferred but you can also provide a postal address or number. (Note: We will not publish these contact details.)
	Conta	act details:
5.	Data pr	rotection declaration
	_	confirm that I have read and understood the Privacy Notice which explains how my personal data will be used.
		are under 12 and making a submission, we will need to contact you to ask arent or guardian to confirm to us that they are happy for you to send us ews.
	F	Please tick this box if you are under 12 years of age.
You	r view	s on the proposal
		vers to the questions in this section may be published (unless your not for publication").
<b>Aim</b> 1.		approach of the following best expresses your view of the proposed Bill?
		Fully supportive

	Partially supportive Neutral (neither support nor oppose) Partially opposed Fully opposed Unsure
Pleas	e explain the reasons for your response.
-	ou think legislation is required, or are there are other ways in which the Bill's could be achieved more effectively? Please explain the reasons for your nse.
assist	n of the following best expresses your view of the proposed process for ted dying as set out at section 3.1 (Step 1 - Declaration, Step 2 - Reflection d, Step 3 - Prescribing/delivering)?
	Fully supportive Partially supportive Neutral (neither support nor oppose) Partially opposed Fully opposed Unsure
be an be rei	e explain the reasons for your response, including if you think there should by additional measures, or if any of the existing proposed measures should moved. In particular, we are keen to hear views on Step 2 - Reflection d, and the length of time that is most appropriate.
	n of the following best expresses your views of the safeguards proposed in on 1.1 of the consultation document?
	Fully supportive Partially supportive Neutral (neither support nor oppose) Partially opposed Fully opposed Unsure
Pleas	e explain the reasons for your response.

5.	Which of the following best expresses your view of a body being responsible for reporting and collecting data?
	<ul> <li>Fully supportive</li> <li>Partially supportive</li> <li>Neutral (neither support nor oppose)</li> <li>Partially opposed</li> <li>Fully opposed</li> <li>Unsure</li> </ul>
	Please explain the reasons for your response, including whether you think this should be a new or existing body (and if so, which body) and what data you think should be collected.
6.	Please provide comment on how a conscientious objection (or other avenue to ensure voluntary participation by healthcare professionals) might best be facilitated.
Fina	ancial implications
7.	Taking into account all those likely to be affected (including public sector bodies, businesses and individuals etc), is the proposed Bill likely to lead to:
	a significant increase in costs some increase in costs no overall change in costs some reduction in costs a significant reduction in costs don't know
	Please indicate where you would expect the impact identified to fall (including public sector bodies, businesses and individuals etc). You may also wish to suggest ways in which the aims of the Bill could be delivered more cost-effectively.

# **Equalities**

3.	What overall impact is the proposed Bill likely to have on equality, taking account of the following protected characteristics (under the Equality Act 2010): age, disability, gender re-assignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation?
	<ul> <li>☐ Positive</li> <li>☐ Slightly positive</li> <li>☐ Neutral (neither positive nor negative)</li> <li>☐ Slightly negative</li> <li>☐ Negative</li> <li>☐ Unsure</li> </ul>
	Please explain the reasons for your response. Where any negative impacts are identified, you may also wish to suggest ways in which these could be minimised or avoided.
Sus	stainability
9.	In terms of assessing the proposed Bill's potential impact on sustainable development, you may wish to consider how it relates to the following principles:
	<ul> <li>living within environmental limits</li> <li>ensuring a strong, healthy and just society</li> <li>achieving a sustainable economy</li> <li>promoting effective, participative systems of governance</li> <li>ensuring policy is developed on the basis of strong scientific evidence.</li> </ul>
	With these principles in mind, do you consider that the Bill can be delivered sustainably?
	<ul><li>☐ Yes</li><li>☐ No</li><li>☐ Unsure</li></ul>
	Please explain the reasons for your response.

# General

10.	Do you have any other additional comments or suggestions on the proposed I (which have not already been covered in any of your responses to earlier questions)?	

## How to respond to this consultation

You are invited to respond to this consultation by answering the questions in the consultation and by adding any other comments that you consider appropriate.

## Format of responses

You are encouraged to submit your response via an online survey (Smart Survey) if possible, as this is quicker and more efficient both for you and the Parliament. However, if you do not have online access, or prefer not to use Smart Survey, you may also respond by e-mail or in hard copy.

#### Online survey

To respond via online survey, please follow this link: <a href="https://www.smartsurvey.co.uk/s/AssistedDyingProposal/">https://www.smartsurvey.co.uk/s/AssistedDyingProposal/</a>

The platform for the online survey is Smart Survey, a third party online survey system enabling the SPCB to collect responses to MSP consultations. Smart Survey is based in the UK and is subject to the requirements of the General Data Protection Regulation (GDPR) and any other applicable data protection legislation. Any information you send in response to this consultation (including personal data) will be seen by the MSP progressing the Bill and by staff in NGBU.

Further information on the handling of your data can be found in the Privacy Notice, which is available either via the Smart Survey link above or here: Privacy Notice.

Smart Survey's privacy policy is available here: <a href="https://www.smartsurvey.co.uk/privacy-policy">https://www.smartsurvey.co.uk/privacy-policy</a>

#### Electronic or hard copy submissions

Responses not made via Smart Survey should, if possible, be prepared electronically (preferably in MS Word). Please keep formatting of this document to a minimum. Please send the document by e-mail (as an attachment, rather than in the body of the e-mail) to:

#### Liam.McArthur.msp@parliament.scot

Responses prepared in hard copy should either be scanned and sent as an attachment to the above e-mail address or sent by post to:

Liam McArthur MSP Scottish Parliament Edinburgh EH99 1SP Responses submitted by e-mail or hard copy may be entered into Smart Survey by my office or by NGBU.

If submitting a response by e-mail or hard copy, please include written confirmation that you have read and understood the Privacy Notice (set out below).

You may also contact my office by telephone on (0131) 348 5699.

## Deadline for responses

All responses should be received no later than **Wednesday 22<sup>nd</sup> December 2021**. Please let me know in advance of this deadline if you anticipate difficulties meeting it. Responses received after the consultation has closed will not be included in any summary of responses that is prepared.

## How responses are handled

To help inform debate on the matters covered by this consultation and in the interests of openness, please be aware that I would normally expect to publish all responses received (other than "not for publication" responses) on the website <a href="https://www.assisteddying.scot">www.assisteddying.scot</a>

Published responses (other than anonymous responses) will include the name of the respondent, but other personal data sent with the response (including signatures, addresses and contact details) will not be published.

Where responses include content considered to be offensive, defamatory or irrelevant, my office may contact you to agree changes to the content, or may edit the content itself and publish a redacted version.

Copies of all responses will be provided to the Scottish Parliament's Non-Government Bills Unit (NGBU), so it can prepare a summary that I may then lodge with a final proposal (the next stage in the process of securing the right to introduce a Member's Bill). The <a href="Privacy Notice">Privacy Notice</a> explains more about how the Parliament will handle your response.

If I lodge a final proposal, I will be obliged to provide copies of responses (other than "not for publication" responses) to the Scottish Parliament's Information Centre (SPICe). SPICe may make responses available to MSPs or staff on request.

# Requests for anonymity or for responses not to be published

If you wish your response to be treated as anonymous or "not for publication", please indicate this clearly. The Privacy Notice explains how such responses will be handled.

## Other exceptions to publication

Where a large number of submissions is received, particularly if they are in very similar terms, it may not be practical or appropriate to publish them all individually. One option may be to publish the text only once, together with a list of the names of those making that response.

There may also be legal reasons for not publishing some or all of a response – for example, if it contains irrelevant, offensive or defamatory content. If I think your response contains such content, it may be returned to you with an invitation to provide a justification for the content or to edit or remove it. Alternatively, I may publish it with the content edited or removed, or I may disregard the response and destroy it.

#### **Data Protection**

As an MSP, I must comply with the requirements of the General Data Protection Regulation (GDPR) and other data protection legislation which places certain obligations on me when I process personal data. As stated above, I will normally publish your response in full, together with your name, unless you request anonymity or ask for it not to be published. I will not publish your signature or personal contact information. The <a href="Privacy Notice">Privacy Notice</a> sets out in more detail what this means.

I may also edit any part of your response which I think could identify a third party, unless that person has provided consent for me to publish it. If you wish me to publish information that could identify a third party, you should obtain that person's consent in writing and include it with your submission.

If you consider that your response may raise any other issues under the GDPR or other data protection legislation and wish to discuss this further, please contact me before you submit your response. Further information about data protection can be found at: <a href="https://www.ico.gov.uk">www.ico.gov.uk</a>.

## Freedom of Information (Scotland) Act 2002

As indicated above, NGBU may have access to information included in, or provided with, your response that I would not normally publish (such as confidential content, or your contact details). Any such information held by the Parliament is subject to the requirements of the FOISA. So, if the information is requested by third parties the Scottish Parliament must consider the request and may have to provide the information unless the information falls within one of the exemptions set out in the Act. I cannot therefore guarantee that any such information you send me will not be made public should it be requested under FOISA.

Further information about Freedom of Information can be found at: www.itspublicknowledge.info.