

Dignity in Dying Scotland submission to the Inquiry on ‘Human Rights and the Scottish Parliament’.

Overview

The current law which outlaws assisted dying in Scotland prevents terminally ill people exercising their right to choice and control as they approach death. It results in dying people having to suffer against their wishes. Currently, one person every eight days is travelling from the UK to Switzerland in order to end their life. Those that can't afford it, are too unwell to travel or don't want to have to die early when they are still able to make the journey, end their own lives in this country, often alone and in traumatic circumstances. Action is needed to respect and protect people's human rights.

Dignity in Dying is a campaign and membership organisation evidencing the need for change across the UK. We believe that everybody has the right to a good death, which should include the option of assisted death for terminally ill, mentally competent adults. Dignity in Dying believes that the Scottish Parliament must legislate to respect, protect and fulfil the human rights of individuals who are terminally ill and who would like control over their suffering at the end of life. Legal reform is permitted under Article 1 of the European Convention on Human Rights (ECHR) which requires States to secure for everyone within their jurisdiction, the rights and freedoms defined in the ECHR.

As the Equalities and Human Rights Committee of the Parliament (EqHRC) is considering how it can enhance its approach to promoting and protecting human rights, we feel it is urgent that the scope of their Inquiry considers assisted dying as a key human rights issue for individuals and their families. At the core of this debate is how to reconcile potentially competing values: the desire of dying individuals to choose to control the manner and timing of their death, and the need to uphold the inherent right to life of every person, as recognised by Article 2 of the European Convention on Human Rights (ECHR)ⁱ and Article 6(1) of the International Covenant on Civil and Political Rights (ICCPR)ⁱⁱ.

- However, by legislating to enable individuals to have the choice of an assisted death a number of separate human rights are engaged, and collectively can be used to introduce safeguards which ensure outcomes which deliver fairness, respect, equality, dignity and autonomy (self-rule) for individuals. In coming to this view, we have drawn on the following ECHR rights: Article 3 – an absolute ban on inhuman and degrading treatment
- Article 6 – a right to a fair process or hearing if a public authority is making a decision that has an impact upon your civil rights or obligations.ⁱⁱⁱ
- Article 8 – the right to respect for private and family life
- Article 10 – the right to receive and impart information in order to form an opinion
- Article 13 – the right to an effective remedy when ECHR rights are being violated

- Article 14 – the right to equal enjoyment of ECHR rights

Under European and International Human Rights Law, there is an obligation on States to respect, protect and fulfil people’s human rights. Therefore, it is appropriate that the issue of assisted dying is thoroughly examined by the Scottish Parliament and we believe that the EqHRC is the right Committee to do so. Legal reform is supported by the public: a clear majority of people in Scotland who support a change in the law, as such the Scottish Parliament will have public support in legislating to deliver this human right. **By adopting human rights standards, an effective process of checks and controls can be incorporated into Scots law so that individual can exercise free and informed choice.**

Elected Parliaments around the world have delivered this human right including the devolved Parliament in the State of Victoria in Australia (2017), the US states of Oregon (1997), Washington (2009) Vermont (2013), California (2016), Colorado (2016) and the District of Columbia (2016) the Province of Quebec (2014), as well as in countries including the Netherlands(2002), Belgium (2002), and Canada (2016).In addition a court ruling in Montana (USA) rules that physicians are authorised to provide medical aid in dying to terminally ill, competent adults (2009). In Switzerland the penal code (1942) makes clear that aiding another to end their life is not a crime so long as the assister’s motivations are non-selfish.

Respecting Choice and Complying with Human Rights Law

The current legal framework in relation to assisted dying clearly has many negative impacts in terms of equalities and human rights:

“...Our outdated laws discriminate between rich and poor, discourage proper conversations between patients and their doctors, criminalise grieving relatives who spend time with their loved ones in their dying moments and oblige people to end their lives before they are ready. Worst of all, while they are predicated on preserving the sanctity of life, they show no mercy to those facing an agonising death, and deny free will to those whose lives and deaths depend upon it.

Kit Malthouse MP, (then) Chair, Choice at the End of Life All-Party Parliamentary Group, in the Foreword to ‘The True Cost: How the UK outsources death to Dignitas’^{iv}.

Human rights law provides the justification for action and the framework for legal reform to ensure the right checks and balances are in place for individuals, their families as well as professionals involved in their care such as doctors and nurses.

Human Rights Law

Human Rights in Scotland

Human rights law in Scotland is framed by the interpretation of international and European human rights legal instruments. There is clearly a need to better mainstream human rights into culture, practice and policy as well as in the detail of Scot’s law. There is a duty on States, which are the duty bearers, to take deliberate and progressive steps to prevent as well as address human rights abuses. . Article 1 of the ECHR obliges States to “respect the rights and freedoms it embodies; it also

has the consequence that, in order to secure the enjoyment of those rights and freedoms, those authorities must prevent or remedy any breach at subordinate levels.”^v Importantly failing to act is also understood to be a breach of a State’s responsibilities. In addressing issues such as legislating for dignity in dying, the Scottish Parliament can be assisted by understanding the relevance and application of human rights law as well as learning from other elected Governments which have chosen to act.

Guidance from the UN

The UK has ratified the ICCPR and other UN treaties, which means that all our laws and policies should comply. Those treaties include the UN Convention on the Rights of the Child, the Convention Against Torture and the UN Convention on the Rights of People with Disabilities. In addition to the text of the articles within the treaties, the lead Committee issues ‘General Comments’ which provide updates as well as clarification on how those articles should be interpreted by States. The UN Committee on Human Rights which is responsible for monitoring the ICCPR has drafted a General Comment on the ‘Right to Life’ which addresses dignity in dying. The latest version states:

“...At the same time, States parties [may allow] [should not prevent] medical professionals to provide medical treatment or the medical means in order to facilitate the termination of life of [catastrophically] afflicted adults, such as the mortally wounded or terminally ill, who experience severe physical or mental pain and suffering and wish to die with dignity. In such cases, States parties must ensure the existence of robust legal and institutional safeguards to verify that medical professionals are complying with the free, informed, explicit and, unambiguous decision of their patients, with a view to protecting patients from pressure and abuse.

“When private individuals or entities are empowered or authorized by a State party to employ force with potentially lethal consequences, the State party is under an obligation to ensure their actual compliance with article 6 and remains directly responsible for any failure to comply with the provisions of article 6. Among other things, it must rigorously limit the powers afforded to private actors and provide strict and effective measures of monitoring and control in order to ensure, inter alia, that the powers granted are not misused, and do not lead to arbitrary deprivations of life.
...^{vi}

ECHR and domestic courts

In *Pretty v United Kingdom* (2002) the European Court did not hold that there had been a violation of Diane Pretty’s article 8 rights but acknowledged that the exercising choice at the end of life falls within the range of right to private life. At 35 EHRR 1, para 67, the court said:

“The applicant in this case is prevented by law from exercising her choice to avoid what she considers will be an undignified and distressing end to her life. The Court is not prepared to exclude that this constitutes an interference with her right to respect for private life as guaranteed under article 8(1) of the Convention....” More recently in the UK courts the House of Lords in *R v Purdy* [2009] UKHL 45, and the Supreme Court in *R (on the application of Nicklinson and another) (Appellants) v Ministry of*

Justice (Respondent) [2014] UKSC 38 have made clear that article 8 encompasses an individual's decisions about the end of their life and their death and that this article is engaged by domestic laws impacting the individual's ability to exercise decisions.

The Council of Europe has produced a review of cases that have been considered and which provide guidance on the latest interpretation of ECHR rights and their interaction.^{vii} In the analysis, it is repeatedly the view of the European Court of Human Rights and the Grand Chamber that it is a matter for the domestic Parliaments. The Grand Chamber has ruled in several relevant cases including Haas V Switzerland (2011), in which:

“The Court noted in particular that the member States of the Council of Europe were far from having reached a consensus as regards the right of an individual to choose how and when to end his life. Although assistance in suicide had been decriminalised (at least partly) in certain member States, the vast majority of them appeared to attach more weight to the protection of the individual's life than to his right to end it. The Court concluded that States had a wide margin of appreciation in such matters.

“Although the Court further accepted that the applicant might have wished to commit suicide in a safe and dignified manner and without unnecessary pain, it nevertheless considered that the requirement under Swiss law for a medical prescription in order to obtain sodium pentobarbital had a legitimate aim, namely to protect people from taking hasty decisions and to prevent abuse, the risks of which should not be underestimated in a system that facilitated access to assisted suicide. The Court considered that the requirement of a prescription, issued on the basis of a thorough psychiatric assessment, was a means of satisfying the obligation on States to put in place a procedure capable of ensuring that a person's decision to end his/her life did in fact reflect his/her free will.”^{viii}

Clearly it is up to elected Parliaments to pass laws which can enable 'dignity in dying'. Countries are permitted a 'margin of appreciation' in interpreting the ECHR to fit their culture and priorities. The Scottish Parliament can and should act on this matter.

Interpreting the articles of the ECHR, is facilitated by understanding the case decisions of the European Court and the Grand Chamber. This will help the Committee's work. For example, for Article 3 to be engaged, the case has to meet the threshold either via a single act or as a result of a set of acts/failings/omissions. In Scotland, we need to better understand how people suffer in dying, and what steps the State can take to prevent that suffering. Therefore, launching a consultation on a proposal for legal reform will ensure an informed flow of evidence that will ensure the draft legislation is fit for purpose.

Role of NHRIs

Assisted dying is an issue that has been addressed by other National Human Rights Institutions (NHRIs). For example, the Australian Human Rights Commission in 2016 published 'Euthanasia, human rights and the law'. There is clearly a role for both the EHRC and the SHRC to inform the work of the Committee and ensure that

human rights as well as the State's duty to act are adequately addressed in the evidence.

Introducing assisted dying legislation on human rights grounds in The State of Victoria, Australia

Scotland has consistently demonstrated a willingness to learn from practice elsewhere and carve a distinctive legislative path, from the rest of the UK. Looking at what other devolved legislatures have done is instructive.

Law reform was achieved by the work of Parliament and the government in the State of Victoria. The Legal and Social Issues Committee published its report in June 2016 which found that one terminally ill Victorian was taking their own life every week. Amongst other things, it recommended that the Victorian Government "introduce a legal framework for assisted dying... based on the assisted dying framework outlined in this report". The Voluntary Assisted Dying Bill was a Government Bill introduced by Victorian Premier Daniel Andrews. The Bill was subject to rigorous parliamentary scrutiny^{ix} and a Ministerial Advisory Panel on Voluntary Assisted Dying.^x The Bill was passed on the November 2017 and will allow terminally ill adults the option of an assisted death in their final months of life, after compliance with rigorous safeguards. Under the legislation, Victorians with a terminal illness will be able to obtain a lethal drug within 10 days of asking to die, after completing a three-step process involving two independent medical assessments.

To be eligible:

- They must be over the age of 18, of sound mind, have lived in Victoria for at least 12 months and be suffering in a way that "cannot be relieved in a manner the person deems tolerable".
- The patient must administer the drug themselves, but a doctor can deliver the lethal dose in rare cases where someone was physically unable to end their own life.
- The legislation includes 68 safeguards, including new criminal offences to protect vulnerable people from abuse and coercion, and a special board to review all cases.

Human Rights Culture and Practice

The Charter of Human Rights and Responsibilities Act 2006^{xi} requires all public authorities in the State of Victoria to consider human rights when making decisions, developing policies and providing services. The Act also ensures that public policy has a human rights focus in the devolved legislature. That legal, policy and cultural environment, fits Scotland and provides a model which can be adapted.

Importance of High Quality, Informed Evidence

A key issue is ensuring that evidence is gathered and processed to inform the debate. Evidence from the Victorian State Coroner, John Olle, was persuasive confirming that palliative care is not enough in some circumstances, and that "the status quo is not working – too many people are having a bad death". The Victorian Coroner reported that between January 2009 and December 2013, there were 2879 suicide deaths in Victoria, of whom around 240 (1 in 12) were by people

experiencing an irreversible deterioration in physical health due to disease. In essence, one dying Victorian took their own life every week. In response to a question about whether palliative care or other support services could prevent such suicides, he said: "... the people we are talking about in this small cohort have made an absolute clear decision. They are determined. The only assistance that could be offered is to meet their wishes, not to prolong their life."

Family members, the Coroners Court of Victoria and Victoria Police gave evidence about how people experiencing an irreversible deterioration in health are taking their own lives in desperate but determined circumstances. Acting Commander of Victoria Police Rod Wilson described the impact of these suicides on first responders and described taking statements from families who were "family members who are clearly desperate and frustrated with the system".

Public Opinion in Scotland

In Scotland 77% are in favour of legalised assisted dying for terminally ill people near the end of their life.^{xii} A further breakdown shows that 49% 'strongly support' whereas only 2% 'strongly oppose'. It is very unusual to find an issue where anywhere near that proportion of people who feel very strongly. A national poll, conducted for Dignity in Dying also shows that the clear majority of Scots, at 76% overall, want their MP/ MSP to support this change; 70% of all Scots said they would be positive towards an MP who supported it. Further research has shown that over half of Scots would consider travelling abroad for an assisted death if terminally ill; yet only a fifth could afford it.

"When I realised how things could go with MND I knew that I would want the choice of an assisted death when the time came. I joined Dignitas. I worry though – I am going to have to travel there when I'm still in reasonable shape and that could be taking years off my life. I worry if I leave it too late I will be trapped. I hate having to make that choice – go early and lose time or get trapped and suffer.

I have to be careful with my money because I know I need it for Switzerland and I'm one of the lucky ones who have enough set aside to pay for it. I find it difficult that there is nobody I can talk to about this."

Dave Finlayson, aged 67, Dundee. Dave has Motor Neurone Disease.

"When it is the end, I want to be at home with my family around me, not in a hospice or hospital. I want how and when I die to be my choice. I would like the choice of assisted dying as I don't want to have to either wait until it is too late or have to take steps to end my life too early. I don't want to lose time. I want to die in a dignified way that allows us all to celebrate my life and acknowledge its worth."

Yvonne Pryor, aged 53, Edinburgh. Yvonne had colorectal cancer. Sadly Yvonne died in October 2017.

Conclusions and Recommendations

Omitting action is not an option. We hope the Committee will give this issue careful consideration. The issue has previously been debated by the Scottish Parliament but there was insufficient focus on the three ways human rights are engaged: legislating

for the human right to have dignity in dying for the individual and their family; citing human rights law to justify the duty on the State to legislate using devolved powers; using human rights law and standards to provide a system that introduces proper checks and balances.^{xiii} There was also a lack of input from dying people and their loved ones. Scotland can lead the way within the UK, and legislate to express its distinctive progressive values. We request that the Committee takes the following action:

1. Accept that there needs to be a political and legal solution to address the human experience of avoiding suffering and injustice.
2. Acknowledge that a range of human rights and responsibilities are engaged in providing everyone with the right to a good end of life and a good death, including the option of assisted dying for terminally ill, mentally competent adults.
3. As the Scottish Parliament is a duty bearer under human rights law, the Committee should agree to set up an "Inquiry into End of Life Choices"^{xiv}, with a commitment to report in 6 months. By receiving high quality evidence, it is in a better position to make informed decisions on the next legislative steps.

We would welcome the opportunity to deliver oral evidence to the Committee and share our perspectives and information.

For further information contact: Alyson Thomson, Director, Dignity in Dying Scotland.

ⁱ Available on the Council of Europe website at

https://www.echr.coe.int/Documents/Convention_ENG.pdf

ⁱⁱ Available on UN website at <http://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx>

ⁱⁱⁱ For a more detailed analysis of what this right is see the EHRC website at

<https://www.equalityhumanrights.com/en/human-rights-act/article-6-right-fair-trial>

^{iv} Available at https://cdn.dignityindying.org.uk/wp-content/uploads/DiD_True_Cost_report_FINAL_WEB.pdf

^v Para 9 'Guide to Article 1 of the ECHR' published by the Council of Europe, December 2017, at

https://www.echr.coe.int/Documents/Guide_Art_1_ENG.pdf

^{vi} Paras 10-11, available on UN website at

http://www.ohchr.org/Documents/HRBodies/CCPR/GCArticle6/GCArticle6_EN.pdf A further draft of the GC was discussed on 2nd November 2017 and its progress to adoption can be monitored at

<http://www.ohchr.org/EN/HRBodies/CCPR/Pages/CCPRIndex.aspx>

^{vii} Factsheet 'End of Life and the ECHR' available on the Council of Europe website at

^{viii} Ibid

^{ix} Extensive list of facts, information and resources available at

<https://www.parliament.vic.gov.au/publications/research-papers/download/36-research-papers/13834-voluntary-assisted-dying-bill-2017>

^x [Ministerial Advisory Panel on Voluntary Assisted Dying: Final Report](#)

^{xi} Available on the Victoria Commission for Human Rights website at

http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubLawToday.nsf/e84a08860d8fa942ca25761700261a63/7379cff5e33da38dca257d0700051af8!OpenDocument&Highlight=0,Act

^{xii} Populus polling, Oct 2017

^{xiii}

^{xiv} This replicates the title of the Inquiry in the State of Victoria

<https://www.parliament.vic.gov.au/publications/research-papers/download/36-research-papers/13834-voluntary-assisted-dying-bill-2017>