

THE AD HOC COMMITTEE ON A BILL OF RIGHTS FOR NORTHERN IRELAND.

A RESPONSE FROM MY DEATH, MY DECISION.

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About us

My Death, My Decision is a grassroots not-for-profit campaign group, which advocates for a change in the law to allow those who are terminally ill or incurably suffering the option of a legal, safe, and compassionate assisted death.

We were founded to represent the interests of those facing constant and unbearable suffering, at a time when no other right to die organisation would, and to advocate on their behalf to secure a lasting change in the law. We have quickly become one of the leading assisted dying organisations in England and Wales. We are advised by an expert medical group, are a founding member of the UK Assisted Dying Coalition, and at the forefront of social change: nearly 90% of the public now favours a change in the law to allow assisted dying for those who are incurably suffering or terminally ill.¹

Summary of our response

We welcome the opportunity to respond to the Committee on A Bill of Rights For Northern Ireland's important consultation. We strongly endorse the forward-thinking nature of this committee's inquiry and investigation into having 'more rights than those we already have through the European Convention on Human Rights'. We do so for two reasons. Firstly, we are unconvinced by claims that legal rights - which is to say legally enforceable protections which apply to everyone but are designed to defend a particular interest - are immutable conceptions, and instead, think they exist to reflect a broad consensus within a society at any given point in time. Secondly, we believe the framework of analysis that legal rights provide has an important value within society, as it enables the voices of those who might otherwise be marginalised to be put at the forefront of debates. Hence, we strongly endorse the purpose of this committee.

My Death, My Decision makes this submission on behalf of our members and supporters in Northern Ireland. The subject of assisted dying is particularly pertinent in Northern Ireland for two reasons. First, due to a lack of commercially available flights from Northern Ireland to Zurich, residents of Northern Ireland are uniquely disadvantaged within the United Kingdom at the end of their life, because the possibility of travelling to a Swiss assisted dying organisation, such as Dignitas, is near impossible. Secondly, at the moment the Oireachtas (Parliament) in the Republic of Ireland is considering a private members bill which, if passed, might legalise assisted dying for everyone on the island of Ireland. As such, a disparity in the rights recognised North and South of the border may imminently arise, thus meaning it is especially apt for this committee to consider the case for a legal right to die.

In this submission, we will focus on the case in favour of recognising a right to die with dignity. Although we recognise the committee might have legitimate questions about the practical implications of such a right, or its relationship among other protections, we will not address these concerns here. This is because, we think questions about the recognition and realisation of rights are logically distinct. In other words, we think determining the existence of a legal right to die with dignity, involves different considerations from questions concerning its appropriateness, limitations, and availability.

In brief, our views are as follows:

- Although we support the principle of non-regression for rights, legal rights should evolve to reflect new circumstances and consensuses.

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

- A right to die with dignity should be recognised within a Bill of Rights for Northern Ireland, because it is one of the most important expressions of autonomy.
- A right to die with dignity exists within autonomy rights, because: (i) the ability to control our lives covers all aspects of lived experience, and the process of dying is a lived experience, (ii) autonomy entitles people to act in ways that are potentially harmful to themselves, and (iii) autonomy ensures not only the absence of barriers, but also the enabling conditions necessary to make free choices.

Our response

In our view, legal rights are neither transcendent concepts nor self-evident truths. Although we strongly support the principle of non-regression on rights, we do not believe new rights are merely discovered. Indeed, the speed and breadth at which new legal rights emerged throughout the 20th century arguably puts paid to such an argument. Instead, we believe that rights exist as a result of an evolving political consensus, and the purpose of recognising 'new rights', is to crystallize the protections they afford to certain interests in our law.

Consequently, we contend that Northern Ireland's proposed Bill of Rights is unlikely to contain entirely novel additions. Instead, we believe the task of this committee is to identify novel applications or expressions of existing rights, which are nevertheless deserving of protection under the law. It is on this basis that we advance the case in favour of recognising a right to die with dignity, which we believe falls under the umbrella of autonomy.

Autonomy

The protection of individual personal autonomy and its sphere of decision-making has long been recognised as a hallmark of free and equal societies. In any given society, a plurality of opinions will exist on the right way someone should live their life; free societies therefore respect autonomy, because they deem individuals as the best arbiters of their own interests.

Aside from this, allowing someone to live their life in accordance with their own conscience, convictions, and values also has normative weight because of the fundamental importance of autonomy to personhood. Autonomy not only gives us control over how we live in a positive sense, i.e. the freedom to choose one option among many alternatives; it also endows us with an ability to be held morally responsible for the consequences of our actions. As such, it is instrumental to an individual's personhood, because it is the ability to make free choices that gives our lives meaning and their purpose.

Autonomy and dying

Rights to autonomy can arise in a variety of situations and range from personal privacy rights, protections for sexuality, freedoms for personal expression/identity, and bodily autonomy in the context of abortion. Importantly, it also arises in the context of end-of-life care because arguably the most important expression of autonomy is choosing whether one continues to live or not.

There are three reasons why a right to die with dignity exists within a broader notion of autonomy:

1. The protections of a legal right to autonomy extend to all aspects of living, including the process of dying. Unlike the state of existence that is 'death', dying is an active experience. Consequently, an individual can legitimately wish to influence how they experience this aspect of living e.g. someone can legitimately wish to have a dignified end of life, rather than a painful, drawn-out, or bleak experience.
2. Assuming an individual is free to act as they wish, it follows that they must also be free to act in a manner which directly harms themselves; provided the harm is limited to themselves alone. This can range from fairly trivial decisions, such as decisions we know to have harmful effects upon our health e.g. smoking and driving; to more fundamental expressions of autonomy, such as the choice to continue living or not.
3. Genuine decisional autonomy cannot merely refer to the absence of obstacles, barriers, or constraints upon our liberty. Rather, in cases where someone is unable to realise their free decision, by virtue of an illness or disease beyond their control, the right to self-determination must also extend to protecting the conditions which are necessary for someone to exercise free choice. In the case of a right to die with dignity, this would mean enabling another person to help someone who is physically incapable of ending their life in a dignified manner, to do so – suicide itself being a lawful act.

5 Hansard, 'Coronavirus Regulations: Assisted Deaths Abroad', Vol 683, Nov 2020, Column 475. Available at: <https://hansard.parliament.uk/commons/2020-11-05/debates/A10D8E3C-C301-4163-890F-775B6E48F192/CoronavirusRegulationsAssistedDeathsAbroad>

6 Andrew Gregory, 'My Dignitas flight to beat lockdown', The Times Newspaper (2020). Available at: <https://www.thetimes.co.uk/article/my-dignitas-flight-to-beat-lockdown-m3gqtcsv7>

Dying as a part of living

It is important to be clear that the notions of 'dying' and 'death', whilst related, are not synonymous concepts. An individual is dead at the point when their life is deemed to no longer be present. However, up and until that point, an individual who is dying still has legal interests and is able to rely upon rights such as rights to autonomy.²

As My Death, My Decision's patron, Professor A.C. Grayling, has persuasively argued:

'Dying is an act of living. It is indeed one of the most important events in life, and because it can be pleasant or painful, timely or untimely, tragic or desired, it is central to the character and quality of a person's life as he himself experiences it. We do not experience death, which is not an activity but a state – a state of non-existence indistinguishable from being born. But we do very much experience dying, just as we hope that most of our acts of living will be pleasant, we likewise desire that the act of dying should be so too – or, if not pleasant, at the very least not frightening, painful or undignified.'

'In the process of dying, an individual's rights are as fully engaged as at any other time in normal life.'³

Given that dying is therefore a part of living, we believe a right to autonomy must apply to our experience of dying. In other words, we think autonomy at the end of life must entitle someone to exercise a choice over how and in what circumstances their death is brought about.

Freedom to make harmful choices

Alternatively, as the well-known harm principle holds, if autonomy truly respects an individual's free ability to make decisions about their own lives, it must follow that people can choose to harm themselves; provided the harm they inflict is only limited to themselves. Of course, it does not follow that this principle is always absolute. For example, in cases where someone is deemed to lack the capacity to reach an informed and well-reasoned decision, bare autonomy should not prevail over every other interest.

A right to die with dignity and 'harm'

This being said, in the context of a right to die with dignity, it is hard to identify the particular harms that would arise. For example, it is sometimes suggested that the harm of an ability to bring about one's own death, is the deprivation of 'future goods' dying brings about. In other words, a right to die with dignity harms an individual by depriving them of future positive experiences. However, as the philosopher Professor Peter Singer has persuasively argued, if someone cannot reasonably expect future positive experiences, or conversely expects their positive experiences to be outweighed by a series of negative experiences, it does not follow that choosing to die means someone is losing anything.⁴ This fact seems particularly compelling, given that it is now a regrettable but unavoidable fact of life, that whilst modern medicine may be capable of extending the duration of someone's life, it cannot equally extend their quality of life. Thus, more people are experiencing unpleasant, undignified, and intolerable periods of suffering before death.

Alternatively, it is sometimes argued that the harm of a right to die with dignity – which is to say choice over how, where, and when we die – is the affront it poses to the special sanctity or value of life. There are, however, multiple reasons to question this view. First, as Professor A.C. Grayling has convincingly argued, it may not be the case that life itself is special, but rather the nature of that individual's life that matters. For example, he argues:

'The 'right to life' cannot mean a right to merely bare existence. It must at least mean a right to a certain minimum experienced quality of life. For example: if someone were confined to a small cage and provided with nothing more than bread and water in perpetuity, this would scarcely be to afford him a life in any acceptable sense.'

'The right to a minimum quality of life, that is, to a minimum quality of experience in any living act, ipso facto applies to the experience of dying. 'Life' in the phrase 'the right to life' is not mere existence. It is existence with at least a minimum degree of quality and value. It means a life in which an individual is protected from arbitrary power and threat, is free to seek opportunities and exercise choice, to enjoy the rewards of endeavours in peace, and to seek and foster personal relationships – and which, to the degree reasonably possible for anyone in this world, is free from distress and pain.'

2 J Coggon, 'Could The Right To Die With Dignity Represent A New Right To Die In English Law', *Medical Law Review* (2006), pp 219-237

3 A.C. Grayling, 'Choosing to have the life and its end that belongs to you', (2018). Available at: <https://www.mydeath-mydecision.org.uk/info/lectures/oct-2018-acgrayling-lecture/>

4 Peter Singer, 'Submission to the Inquiry into End of Life Choices', Parliament of Victoria, Legislative Council, Standing Committee on Legal and Social Issues (2014). Available at: https://www.parliament.vic.gov.au/images/stories/committees/lsc/Submissions/Submission_643_-_Peter_Singer.pdf

'As this implies, mere existence is not automatically a good. If it were, no life- support machine would ever be switched off, and contraception would be outlawed because it limits the sheer accumulation of human numbers... Shortening the dying process, and making it easy and peaceful, expresses consideration for what is meant by a 'right to life' in the fullest sense.'⁵

Similarly, from a religious perspective *My Death, My Decision's* patron, the Revd Canon Rosie Harper, has suggested:

'...When talking about life as sacred you have to define what that is. I had a letter in the post, a big long written letter that I very rarely get from someone in Australia that I only opened [sic] yesterday. He told me the case of someone in his family who had been living technically alive for over three years in a care home. They couldn't speak, they had to have assistance to breath, and assistance to have some sort of nutrition that was being pumped into them. He said "what is there that is sacred about that half-life", a life they didn't want to live and that they pleaded never to be allowed to get into the state of. So when you say sacred I think you have to talk about real life, not the sort of shadow land that some people get trapped in for years and years. Simply because the people around them are afraid and unable to act. Sacred, I think, means real and living life, not some sort of shadow land you can get trapped into.'⁶

Thus, we are unconvinced that, in principle, a right to die with dignity would cause any discernible 'harm'.

Necessary conditions to realise autonomy

Finally, we contend that if the law protects autonomy merely in the sense of allowing individuals a bare freedom to act without external barriers, then this is not a genuine expression of autonomy. Instead, as noted above, we believe the normative value of autonomy stems from the capacity it enables for self-development. In other words, autonomy is valuable because it allows us to take personal responsibility for our actions. If it were the case that autonomy only removed barriers, then it is difficult to understand how personal responsibility could arise for an individual since, in reality, it is easy to conceive of circumstances where indirect socio-economic and cultural barriers would prevent someone from undertaking the actions they wanted to pursue.

In the context of a right to die with dignity, we think this means people not only have a right to exercise a bare choice over how and in what circumstances their death is brought about; their interest also protects the conditions necessary for them to make such a choice. For example, in the case of an adult who has reached an informed, voluntary, well-considered and free decision to end their life, but is unable to physically end their life because of a condition – such as locked-in-syndrome – a right to die with dignity empowers them to request assistance for someone else to help them die.

For the avoidance of doubt, we do not contend that a right to die with dignity entitles someone to bring about the death of an unsuspecting third party. Rather, we believe it entitles someone to legitimately request assistance to bring about their own autonomous wish. Further, we recognise that autonomy in this situation is relational. Namely, although autonomy entitles someone to request assistance from another, it does not entitle someone to demand assistance. Thus, it would be perfectly possible to balance a right to die with dignity alongside robust limitations and safeguards, as well as a right to conscientious objection by anyone receiving a request.

In sum, we, therefore, think that being forced to continue living a life that someone deems to be intolerable is an unjustified violation of their fundamental right to autonomy and that in inviting consideration for additional rights under a Northern Irish Bill of Rights, it would be right for Northern Ireland to take a leading stance by recognising a right to die with dignity.

5 Ibid no.3

6 Revd Canon Rosie Harper, 'Faith & Assisted Dying', *My Death, My Decision* (2019). Available at: <https://www.youtube.com/watch?v=PPCpdKyIhk&t=130s>