

THE GOVERNMENT'S RESPONSE TO COVID-19: HUMAN RIGHTS IMPLICATIONS OF LONG LOCKDOWN. 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 incorporated in 2019 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. Since then we have quickly become one of the leading assisted dying organisations in England and Wales. We are advised by an expert medical group, 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.

Our Response

In this response, we focus on the following question:

'The human rights impacts of extended lockdown restrictions on those areas subjected to the most stringent, lasting, lockdown conditions. What have been the human rights impacts on family life and mental health for those communities? Are there ways that these rights might be better addressed?'

We answer this question with a focus upon the impact lockdown measures have had upon terminally ill and incurably suffering individuals who wish to travel abroad to end their lives.

Assisted Dying and Coronavirus Restrictions

It is well established within the jurisprudence of the European Court of Human Rights that a human right exists to control the manner and timing of one's own death. However, this right is subject to the margin of appreciation and thus its realisation is at the discretion of each member state.² Consequently, it is unlawful in England and Wales to assist another person's death, but it is not against the law for an adult of sound mind to voluntarily travel for an assisted death abroad. In other words, provided an adult travels on their own, our law does not prevent people from ending their lives in foreign countries where assisted dying is permitted,³ such as Switzerland; it is only the accompaniment or encouragement of another person which violates the Suicide Act 1961.

Prior to the introduction of lockdown measures last year, research from the UK Assisted Dying Coalition suggested that on average at least one Briton per week travelled to Switzerland for an assisted death.⁴ Moreover, our analysis of these individuals'

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>

2 *Hass v Switzerland (Application no. 31322/07) (2011), para 51*

3 *Re Z (Local Authority) [2004] EWHC 2817 (Fam)*

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

outward area codes, indicates that a sizable number of people who would typically travel to Switzerland reside in areas which have experienced some of the most severe periods of lockdown restrictions.

Anecdotal evidence and our own experience suggests that there was widespread confusion when lockdown measures were introduced as to whether foreign assisted dying qualified as a 'reasonable excuse' to leave one's home. Indeed, it was not until 5 November 2020 that the Secretary of State for Health and Social Care confirmed that 'travelling abroad for the purpose of assisted dying is a reasonable excuse, so anyone doing so would not be breaking the law',⁵ meaning that for two-thirds of the year a marginalised group of our population potentially forfeited their rights for no good reason. This is all the more worrying, given that on 20 December 2020, Switzerland introduced a travel ban on UK Citizens – which is expected to continue for the foreseeable future – thus meaning Brits who had postponed their decision to travel abroad had a window of only 35 days to obtain the dignified death they hoped for.

The consequences of enduring lockdown restrictions upon terminally ill and incurably suffering people, who would otherwise wish to end their lives abroad, has therefore been two-fold. Firstly, for those 'greenlighted' by a Swiss organisation, namely Dignitas, Lifecircle, EX International, or Pegasos (in other words those with a scheduled date to end their lives) our experience indicates that the vast majority have postponed or missed their scheduled opportunity. This is significant because these organisations have limited capacity and, of course, do not only assist British Citizens; thus if someone misses their opportunity they risk being put 'at the back of the queue'.

Considering that people with degenerative and terminal conditions, not unreasonably, tend to wait until the last possible moment before going to Switzerland, more often than not joining a long waiting list is effectively the same as not being able to have an assisted death. This is because they either become physically incapable of making the necessary journey abroad, or in cases of some conditions, such as dementia, lose the necessary mental capacity to competently request assistance to die. As you will no doubt be able to appreciate, this is an extremely traumatic consequence for people facing constant and unbearable suffering.

At best, it means they face the unenviable prospect of a slow, drawn-out, or painful death; but more often than not, it also means that these people lose the one sense of control they still retained over their lives – the manner and timing of their death. In extreme cases, it can also prompt people to seek out dangerous and unqualified advice about so-called 'self-help' methods, which My Death, My Decision strongly advocates against. In these cases, people already enduring appalling degrees of suffering can face the added nightmare of botched attempts to end their life, or cause unnecessary distress for their loved ones afterwards.

Aside from this, we are aware of at least one case where someone chose to expedite their death because they feared restrictions would prevent them from travelling to Switzerland at a later date. Beyond the obvious implications this has for someone's right to life, a decision to cut short someone's remaining 'good period' of life can be profoundly damaging for both themselves and their close friends and family. In the case of an individual, it is our experience that once someone decides they want to go to Switzerland and gains provisional approval, they experience a real sense of relief and 'new lease of life'. Consequently, most understandably want to spend their final months or years in the company of their loved ones and premature trips to Switzerland rob them of this invaluable time. Indeed, anecdotal evidence suggests that some people may even have chosen to conceal their plans from loved ones, due to concerns that the heightened policing of foreign travel and inevitably scrutiny might prevent them from going abroad at all. Thus, in some cases families can not only lose out on the valuable final months of their loved one's life, but can also be robbed of an opportunity to say goodbye; thus inhibiting their grieving process.

Our recommendation

In view of the above, we encourage the Government to take a more proactive stance on this issue by providing clearer guidance at the outset of any future lockdowns.

Nevertheless, even if the Government were to enact this recommendation, we are conscious that the secretive nature of arranging assisted deaths abroad may mean that these issues arise again. Which is to say nothing of the additional non-lockdown inadequacies and failings of our current law prohibiting assisted dying in England and Wales. Therefore, we encourage the UK Government and Parliament to grasp the issues exposed by the recent lockdown restrictions and take a leading stance by enabling legal, safe, and compassionate assisted dying for adults of sound mind, who are either terminally ill or incurably suffering; as supported by an overwhelming majority of the public.

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>

Whilst we recognise that this is a sensitive issue and that there are legitimate concerns about the legalisation of assisted dying, we believe that the UK should not shy away from these challenges. If anything, the onset of Covid-19 has demonstrated the fragility of end-of-life choices in the United Kingdom and we strongly encourage the UK to follow the example of other progressive nations, such as Canada, by instigating a thorough and widespread examination of our laws on assisted dying and end-of-life care.