DIGNITAS

To live with dignity

To die with dignity

# Assisted Dying Laws and Discrimination

# Inclusion, Exclusion, Consequences and a Way Forward

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Abstract / Key points ..... 2
From taboo to human right ..... 2
A human right ..... 2
Inclusion ..... 3
Exclusion ..... 4
The consequence of exclusion ..... 5
Exclusion through language ..... 6
Further developing inclusion ..... 6
Enhancing the "medical model" ..... 9
Conclusion ..... 10

## Abstract / Key points

Quite a number of laws, including recently enacted ones, permit an individual to end their suffering and life with the assistance of another person such as medical or other professionals – whether the person themselves carries out the act that brings about death or someone else acts on their request – but create discrimination by granting this access to assistance only to certain individuals with specific health conditions and/or limited life expectance while excluding others. The following pages take a brief look at some of the excluded groups and suggests potential ways to enhance inclusion.

## From taboo to human right

For many centuries, due to religious-fundamentalist intolerance and abuse of clerical power, people who had chosen suicide were often buried outside graveyards and sometimes their families were punished, for example by seizure of their property. It was the development of humanism and thinking based on science as well as the growing separation of church and state in the wake of enlightenment, in the 17th/18th century, which brought about the decriminalisation of suicide[1]. There are still some countries which, in their law, criminalise the act of ending one's own life. There are more countries which criminalise the act of assisting another person to end their own life.

In recent years, the number of countries has increased which by law permit an individual to end their own life with the assistance of another person, and/or the assisting person to carry out the act that ends life as requested by the individual[2]. These laws have come about due to peoples' initiatives leading to parliamentary law-making proceedings or court judgments.

## A human right

In Europe, almost all states have adhered to the European Convention on Human Rights (ECHR)[3]. In specific cases, set legal situations may be questioned whether they would be in line with the basic human rights and liberties enshrined in the ECHR. The European Court of Human Rights (ECtHR)[4] has developed an important jurisdiction on basic human rights, including aspects of the right to choose a voluntary death.

In the case of Diane Pretty v. the United Kingdom dated 29 April 2002[5], in

[1] Cf. "Vom Tabu zum Menschenrecht" ("From taboo to human right"), by Ludwig A. Minelli, available in German only so far: http://www.dignitas.ch/images/stories/pdf/diginpublic/artikel-vom-tabu-zum-menschenrecht-aufklaerungundkritik3-4-2020.pdf
[2] Herein referred to as "assistance in suicide" and "voluntary euthanasia", summarised as "assistance in a voluntary death" (AVD)
[3] The Convention: http://www.echr.coe.int/Documents/Convention_ENG.pdf
[4] https://www.echr.coe.int
[5] Application no. 2346/02, http://hudoc.echr.coe.int/eng?i=001-60448

paragraph 65, the ECtHR expressed:

*"The very essence of the Convention is respect for human dignity and human freedom. Without in any way negating the principle of sanctity of life protected under the Convention, the Court considers that it is under Article 8 that notions of the quality of life take on significance."*

On 20 January 2011, in a case brought about by DIGNITAS, the ECtHR rendered the judgment Haas v. Switzerland[6] and stated in paragraph 51:

*"In the light of this case-law, the Court considers that an individual's right to decide by what means and at what point his or her life will end, provided he or she is capable of freely reaching a decision on this question and acting in consequence, is one of the aspects of the right to respect for private life within the meaning of Article 8 of the Convention."*

In this, the ECtHR acknowledged that the freedom to choose the time and manner of one's own end in life is a basic human right.

There are further ECtHR and national court judgments in Canada, Germany, Austria, Italy, Colombia, etc. The bottom line is that these acknowledge that a blanket prohibition of assistance for a person who voluntarily wishes to have an end to their own life violates human and/or constitutional rights and freedoms.

## Inclusion

All recent laws permitting assistance in a voluntary death (AVD) which have developed out of parliamentary law-making proceedings, and which are in the process of being debated or proposed for this, outline certain eligibility criteria to receive assistance in determining the moment of one's own end in life. For example, laws in the USA, Australia, and New Zealand permit medical assistance for an individual wishing to end their life who suffers from a diagnosed illness that will lead to their death within a set number of months. These laws provide an additional option for a specific group of individuals to end their suffering, by means other than palliative care / palliative sedation, discontinuing life-maintaining measures based on an Advance Directive, voluntary stopping eating and drinking (VSED), etc.

There are many testimonials from individuals considering or making use of these laws, and their families, that having such a choice provides relief, improves quality of life, encourages conversation beyond end-of-life-matters, and more.

[6] Application no. 31322/07, http://hudoc.echr.coe.int/eng?i=001-102940

## Exclusion

One of the difficulties raised by respecting an individual's right to end their suffering is the tension that exists between someone wanting to exercise that choice but society – and the law – holding the view that it is "too early" for them to end their life.

Through countries' laws with the aforementioned eligibility criteria of a limited life expectancy and/or that the individual needs a medical diagnosis of an illness that is known to be terminal and/or incurable, several groups of individuals are potentially excluded from the choice of AVD at their home.

### Tetraplegia

Over the years, several tetraplegics, individuals paralysed due to an accident or illness, reached out to DIGNITAS. One was a young rugby player from the UK who, in a sports accident six years earlier, had his neck vertebrae dislocated. In months of therapy, he regained some control over his fingers. On several occasions, he tried to put an end to his situation by do-it-yourself suicide and failed. Finally, he contacted and travelled to DIGNITAS, to make use of a physician-supported AVD, assisted by professionals of DIGNITAS and accompanied by his loved ones. There have been others like him taking the same route, from the UK, Mexico, Germany and other countries.

### Psychiatric diagnosis

The ECtHR judgement in the case of Haas v. Switzerland mentioned earlier involved an individual whose sole underlying diagnosis was a psychiatric illness. It concerned an architect, successful in business, who had struggled with the impact of bipolar affective disorder for some twenty years; he had tried a do-it-yourself suicide twice and he had stayed in psychiatric hospitals on several occasions. Before having his case heard at the ECtHR, he had turned to the Swiss Federal Supreme Court as procedural laws obliged him to do. In its judgment of 3 November 2006[7], the Court found:

*"It must not be forgotten that a serious, incurable and chronic mental illness may, in the same way as a somatic illness, cause suffering such that, over time, the patient concludes that his or her life is no longer worth living. The most recent ethical, legal and medical opinions indicate that in such cases also the prescription of sodium pentobarbital is not necessarily precluded or to be excluded on the ground that it would represent a breach of the doctor's duty of care. […] Where the wish to die is based on an autonomous and all-embracing decision, it is not prohibited to prescribe sodium*

[7] BGE 133 I 58, page 67, consideration 6.3.5.1 (translated) http://bit.ly/BGE133I58

*pentobarbital to a person suffering from a psychiatric illness and, consequently, to assist him or her in committing suicide."*

### Neurodegenerative diagnosis

Multiple Sclerosis, Amyotrophic Lateral Sclerosis, Huntington's Chorea, Parkinson's, and dementias such as Alzheimer's: these are illnesses that can progressively impair an individual's quality of life but not lead to death for many years. With dementia illnesses, such individuals could lose the cognitive capacity required to use AVD laws before they enter the eligibility period. Many people do not wish to experience the decline of their intellectual faculties to become a body without a personality.

### Old age ailment

A few weeks ago, headlines reported that the renowned French-Swiss film director Jean-Luc Godard, at the age of nearly 92, had chosen physician-supported AVD in Switzerland. Some stated that he had not been sick. The fact is that medically diagnosed ailments in connection with his advanced age had impaired his quality of life to the point of him being exhausted. Already, in the judgment of the ECtHR case of Diane Pretty v. the United Kingdom dated 29 April 2002[8], the Court expressed:

*"In an era of growing medical sophistication combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude which conflict with strongly held ideas of self and personal identity."*

### This far but no further

In industrialised "western world" countries, average life expectancy (from birth) has more or less doubled over the past 150 years to have reached over the age of 80. Who does not wish to live longer when staying healthy? Some individuals point out that individual fulfilment, which allows people to shape their life the way they want to lead it and the way they feel to be appropriate in accordance with their personal values – and within the framework of the existing legal and social order – includes departing before losing the quality of life essential to their understanding of personal dignity.

## The consequence of exclusion

The eligibility criteria of a limited life expectancy mentioned earlier, or of a medically diagnosed illness that is terminal or incurable, is sometimes explained to be a safeguard. However, eligibility criteria which exclude groups of individuals to access professional support in AVD leads to them

[8] Application no. 2346/02, http://hudoc.echr.coe.int/eng?i=001-60448

being barred from receiving the advantages of relief, improvement of quality of life, etc. Seriously negative consequences flow from this: either these individuals need to reach out to and travel to DIGNITAS in Switzerland, or they have to try do-it-yourself-action which – whether or not it is guided – has risks for the individual, their loved ones and third persons.

Besides, exclusion constitutes impermissible discrimination which conflicts with the human right and freedom to determine the time and manner of one's own end in life.

## Exclusion through language

During the years, proposed or enacted AVD laws have come up with various wording to describe the act of assisting another person in ending their own life: death with dignity, voluntary assisted dying, medical aid in dying, end-of-life-choice, etc.

In relation to the specific type of AVD used by an individual to end their life, the word "suicide" is avoided. Suicide is seen by some as being affiliated with an irrational act, illegal methods, non-medical or unprofessional assistance and something which triggers negative feelings in the religious, etc. However, it should be remembered that the word "suicide" stems from the Latin "sui caedere" which is the act of taking one's own life, but there is no negative connotation attached to it. In fact, even the Bible mentions several acts of suicide without condemning them.

Whilst it is true that an individual ending their own life under an AVD law does not involve the same process as the act of someone hanging or shooting themselves, to dig a ditch in defence of such AVD being a form of suicide stigmatizes an individual's choice to end their life, confuses the many circumstances that could lead to this decision and introduces exclusion and discrimination. Provocatively said, suicide is labelled as "not worthy for AVD". This upholds the taboo and the negative labelling and stigmatization of anyone who chooses to end their lives, including those who wish to have a legal, safe and professionally assisted end to their suffering and life.

## Further developing inclusion

### Hippocrates' retirement

Occasionally, some medical professionals and opponents of the right to choose one's own end in life and having access to assistance for this, refer to the Hippocratic Oath, an over two-thousand-year-old set of medical ethics standards historically pledged by physicians. They claim that the oath's principle of non-maleficence speaks against getting involved in AVD.

They overlook the fact that this oath sworn by a number of ancient Greek gods, has been replaced by the Declaration of Geneva of the World Medical Association introduced in 1948 and updated since[9]. Taking two points from this Declaration:

*"I will respect the autonomy and dignity of my patient"*

Sometimes, doctors refer to an order, in the sense of a task derived from the medical self-perception / ethos of how to treat a patient. Two aspects are overlooked with this: in legal terms, medical treatment generally constitutes inflicting an injury on another person which is justified only by informing the patient about the consequences and based on the patient's consent. Furthermore, this consent, and with it the order for the treatment, can generally only be done by the patient, at least as long as they can express such an order; possibly an Advance Directive is decisive or the loved ones are to be asked about the patient's best interest. If nothing is requested conflicting with laws in place, the medical professional must follow the patient's orders or decline.

*"I solemnly pledge to dedicate my life to the service of humanity"*

Caring for humanity means taking peoples' values and wish for an end of suffering and life seriously and to extend to them respect, care, compassion, taboo-free communication, and safe, legal end-of-life options. It does not mean excluding them from AVD and thus leaving them to travel abroad or to a do-it-yourself suicide, whether or not it is guided. Paul Lamb, a man paralysed from the neck downward, who went to the UK courts to fight for his right to have assistance in AVD put the point well: *"As easy as it might sound to simply shove me out of the country, I know that I – and many others like me – deserve better treatment."*

## Beyond ICD

Generally, and even more so with the eligibility criteria mentioned earlier, to justify AVD there must be some medical diagnosis. Though maybe not explicitly stated, it is assumed to be one in accordance with the International Classification of Diseases (ICD)[10], currently ICD-10, to be replaced by ICD-11 enacted on 1 January 2022 by the World Health Organization (WHO).

As pointed out earlier however, the root of the wish of an individual for AVD is not necessarily an illness on the list of the ICD, but rather the individual's feeling of impaired quality of life due to not being able to

[9] https://www.wma.net/policies-post/wma-declaration-of-geneva
[10] https://www.who.int/standards/classifications/classification-of-diseases

function (anymore) as they personally desire. Therefore, beyond ICD, the International Classification of Functioning, Disability and Health (ICF) should be considered. The ICF serves as a description of functional state of health, disability, social impact, and relevant environmental factors for an individual. With the ICF, it is not only focused on a diagnosis / illness but beyond this the question to which extent the individual is (still) functioning and able to participate in social life. It seems that the WHO increasingly follows the approach that a medical diagnosis should be established multidimensionally, starting by assessing the impairment in relation to the ICF, which serves as an objective guide for an individual doctor's subjective perception.

## Health is more than not having an illness

As indicated earlier, the definition of illness seems to be led by reference to the ICD. However, thinking beyond ICD, and even beyond ICF, the WHO constitution states[11]:

„*Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.*"

And a further aspect should be noted from this constitution:

*„The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.*"

The latter fits in with the earlier mentioned WMA Declaration of Geneva which states this doctor pledge:

*"I will not use my medical knowledge to violate human rights and civil liberties, even under threat".*

Bringing together the testimonials mentioned earlier about access to AVD improving quality of life, the WHO constitution right to health, and the ECtHR's right to determine the time and manner of one's own end in life, it can be found that AVD is not only a right to die but a right to health.

## A shift of attitude

To assume from the start that an individual's desire for suicide is always a symptom of mental illness and/or an irrational act is a prejudice leading to stigmatization and exclusion. Instead of jumping to conclusions and resorting to labelling, taking a step back to a neutral position on an individual's wish to have an end to their life is necessary: a shift of attitude.

[11] https://www.who.int/about/governance/constitution

Through its work, and in submissions and talks[12], DIGNITAS repeatedly points out that suicide (attempt) prevention and AVD – in fact, all care and end-of-life-options – should go hand in hand because AVD is a form of suicide attempt prevention.

It is important to encourage people to come forward so that their concerns and preferences be considered, with the result that individuals who are suffering from temporary loss of the desire to live can be helped and those whose suffering is enduring can also be helped.

People contemplating ending their own life deserve respect, care, compassion, taboo-free communication, and safe, legal end-of-life options. Not exclusion. Not upholding the taboo on suicide, which harms everyone, including those who seek to use AVD.

## Enhancing the "medical model"

Some propose that the "medical model", which involves medical professionals in AVD and/or makes it a procedure embedded in medical care, should be done away with. There are at least three well-known manuals with professionally researched know-how on self-deliverance, on autonomous ending of one's life, and there are earlier, predecessor publications. Still though, some individuals seem to prefer reaching out to medical and professional assistance and accompaniment for putting into practice their choice of a self-determined end of suffering and life. As pointed out earlier, in the current "medical model" some individuals and even groups are excluded. So far.

One way forward could be to enhance the "non-medical model" of self-deliverance by allowing the support of non-medical professional assistants. However, this still leads to their exposure to investigation and possible negative consequences by police, state attorney, etc., and in connection with this it may be necessary to provide proof of an assessment of capacity of judgment – which usually includes medical professionals.

The solution could be not to work with two separate models but to bring them together. For this, again, a shift of attitude is necessary: the medical model of AVD, especially with laws determining eligibility criteria which exclude the earlier mentioned groups, needs to be enhanced and improved upon to bring it in line with the freedom and right to decide on the time and manner of one's end in life. The aspects mentioned earlier may offer a

[12] E.g. TEDx "talking taboo", http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-tedxzurich-08072021.pdf

starting point. Most importantly, laws must be shaped to provide legal safety for everyone involved with AVD.

## Conclusion

AVD needs to be understood not as something that is allowed by the grace of someone passing judgment on who is or is not worthy to access professional assistance for it, but as a basic human freedom and right to which, as the ECtHR put it in the case of Haas, every individual should have access to, "*provided he or she is capable of freely reaching a decision on this question and acting in consequence".* AVD is not simply about the right to die, but the right to have one's human dignity, health and care respected by being provided with access to legal medical and professional assistance to safely end one's suffering and life at the time of one's choice.

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