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Forch, 24 August 2018

Call for Public Representations: Draft National Health Amendment Bill, 2018

**Letter by DIGNITAS - To live with dignity - To die with dignity
Forch, Switzerland**

for and on behalf of the 38 South African members of DIGNITAS
submitted in electronic format to speaker@parliament.gov.za and dcarter@parliament.gov.za

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Dear Madam,

In response to the call for written representations on the proposed Draft National Health Amendment Bill, 2018, our non-profit member society DIGNITAS – To live with dignity – To die with dignity (hereafter named ‘DIGNITAS’) wishes to advise that we support the proposed legal recognition, legal certainty and legal enforceability regarding Advance Health Care Directives such as the Living Will and the Durable Power of Attorney for Healthcare.

We would like to use this opportunity to share some information with you:

1) Introduction

“The best thing which eternal law ever ordained was that it allowed us one entrance into life, but many exits. Must I await the cruelty either of disease or of man, when I can depart through the midst of torture, and shake off my troubles? . . . Are you content? Then live! Not content? You may return to where you came from”¹. These are not the words by a protagonist of the many organisations around the world representing the interests of people who wish for freedom of choice in ending one’s suffering and life self-determinedly today, but the words of Roman philosopher LUCIUS ANNAEUS SENECA who lived 2000 years ago, in his letters dealing with moral issues to Lucilius.

In recent years, questions dealing with the subject of end-of-life choices, including assisted suicide and voluntary euthanasia, have arisen again and are now discussed in the public, in parliaments and courts.

Of the many reasons for this development, one is the progress in medical science which leads to a significant prolonging of life expectancy. During the congress of the Swiss General Practitioners in 2011² it was emphasised that a sudden death, for example due to a ‘simple’ heart attack or a stroke is nearly unthinkable today, due to possibilities of modern intensive care.

Obviously, this progress is a blessing for the majority of people. Who would not want to live as long as possible if one’s quality of life, which includes health, is good by one’s personal point of view? However, medical advances have led to a vastly increased capacity to keep people alive without, in some cases, providing any real benefit to their health³ – prolonging life to a point much further in the future than some patients would want to bear it. More and more people wish to add life to their years – not years to their life. Consequently, people who have decided not to carry on living but rather to self-determinedly put an end to their suffering started looking for ways to do so. This development has gone hand in hand with tighter controls on the supply of barbiturates and progress in the composition of pharmaceuticals which led to the situation that those wishing to put an end to their life could not use this particular option anymore for their purpose and had to start choosing more violent methods. The consequence of this: lonely, risky suicide attempts, of which the majority fail, with dire consequences for the individual and his loved ones as well as for third persons.⁴

¹ In: *Epistulae morales LXX ad Lucilium*

² Congress of Swiss General Practitioners in Arosa, 31 March - 2 April 2011

³ British Medical Journal 2012, <http://www.bmjjournals.org/lookup/doi/10.1136/bmjjournals-2011-100532>

⁴ See the speech “Suicide-Prevention must be complemented by Suicide-Attempt-Prevention”:

<http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-wf-kongress-suizidversuche-e-15062012.pdf>

2) Who is DIGNITAS and why does DIGNITAS write this letter?

DIGNITAS is a Swiss not-for-profit member society, a help-to-life and right-to-die dignity advocacy group, founded 17 May 1998 by Swiss human rights attorney-at-law Ludwig A. Minelli. Many years earlier, in 1977, he had already founded SGEMKO, the Swiss Society for the European Convention on Human Rights, a not-for-profit member society spreading information about the European Convention for the Protection of Human Rights and Fundamental Freedom (ECHR). At an early stage, Mr. Minelli and his colleagues have been convinced that where there is the individual's right to life as enshrined in article 2 of the ECHR, there also must be the individual's right to die – the personal right to have control over the end of his or her own life. Many years later, in 2011, the European Court of Human Rights (ECtHR) confirmed this opinion in the case of HAAS v. Switzerland, application no. 31322/07.

DIGNITAS being a human rights orientated organisation posed the question: if in Switzerland, why not in other countries? Isn't it discriminatory, if access to a dignified end of life depends on domicile/residence and citizenship? The ECHR condemns such discrimination in article 14⁵. Therefore, the logic consequence for DIGNITAS was 1) to allow non-Swiss residents and non-Swiss citizens to access the possibility of medically assisted dying (assisted/accompanied suicide) in Switzerland, which obviously includes South Africans, and 2) to advocate for implementation of options to plan ahead in matters of health care, and also 'the last human right', the practice of Switzerland, in other countries too.

Today, DIGNITAS, together with its independent German partner association DIGNITAS-Germany in Hannover, counts 9,400 members worldwide of whom 38 reside in South Africa.

In its 20 years of operation, DIGNITAS has been involved in several leading legal cases dealing with the 'right to die' at the European Court of Human Rights and others more and DIGNITAS has been consulted by committees, panels and representatives of parliaments, from England, Scotland, Sweden, Victoria Australia, Canada and others more, in matters regarding the implementation of laws to introduce choices for individuals so they may plan ahead and put in practice their wishes on controlling their destiny, their final stretch of life.

Many people sign up as members of DIGNITAS because they wish to have the safety for a self-determined end of life. Most of these members, those who suffer from a grievous suffering, will finally make use of palliative care in their home country. However, their biggest fear is to end up in a hospital bed incapacitated, as a "vegetable", deprived of autonomy and therefore other-determined. The safety of knowing that the patient's wishes and will has to be respected by law, because it is implemented in the law, allows patients to better cope with their illness and bear their suffering.

3) Planning ahead

In the 20 years of DIGNITAS' existence, 5 individuals from South Africa have made use of the option of a self-determined self-enacted and physician-supported ending of suffering and life accompanied with DIGNITAS in Switzerland⁶. For all DIGNITAS-members, being assisted and accompanied through the final stage of their life towards their self-

⁵ http://www.echr.coe.int/Documents/Convention_ENG.pdf page 13

⁶ <http://www.dignitas.ch/images/stories/pdf/statistik-ftb-jahr-wohnsitz-1998-2017.pdf>

chosen end was and is an issue of major importance. DIGNITAS always encourages members to have their next-of-kin and friends at their side during the entire process, including the final days.

However, if these South Africans had had more legal safety as to their end-of-life wishes, there would have been the chance for them to find help at home; they would not have had to turn to DIGNITAS and make the strenuous journey to Switzerland to put in practice their wishes in regard of a self-determined end of suffering.

The first and arguably most important step to prepare for the known and the unknown is to think, consider and discuss about end-of-life wishes.

One can only define for oneself whether one's *own* life still holds quality, based on one's personal measure of value. Nobody can gauge whether someone else's quality of life is sufficient. The healthy cannot step into the shoes of a suffering person and judge whether that individual's life has quality, nor can they decide whether or not it makes sense to continue living.

The first step in such preparation is to think about one's *measure* of value in regard to one's own life. What is it that I want to happen in a specific situation, for example when facing a severe illness or if I cannot handle my own affairs anymore? What should happen if, for whatever reason, I can no longer interact with my environment and thus cannot express my will?

One can pose these and many similar questions, think about them, decide on an answer and put these decisions in – preferably written – instructions. Of course it is also possible to decide *not* to decide and not to do any such instructions. This is a personal choice. When it comes to medical instructions, some people think "my doctor will know what is best for me". Of course, this has to be respected and such confidence in medical professionals and a functioning health care is a good thing. Others favour maximum independence and self-determination and they assume responsibility for this by planning ahead.

Whatever one's choice, it is important to discuss one's perception and values concerning "suffering and end-of-life issues" with people one trusts; such people are usually close family member and friends, but could also be one's doctor. An open exchange on one's personal perceptions and wishes creates understanding and trust.

One needs to be aware that matters surrounding one's end in life do not just concern oneself and one's own right to self-determination, but one must also take into account the fact that we all bear a responsibility towards our loved ones. In an emotionally difficult situation, the loss of a loved one is at least a bit less burdensome if people do not have to ask themselves: "What would he/she have wanted?" Preparation also takes into account the position of medical doctors and nurses; they too are relieved if essential questions have been answered in advance.

An Advance Directive is the one probate instrument. Discussing the issue and putting in writing one's wishes at a time when one has capacity of judgment to become effective at a time one has lost capacity for whatever reason, offers important advantages:

- It gives loved ones safety and clarity and relieves them from potentially having to make difficult decisions without knowing the personal wishes of their family member;

- It gives safety and clarity to health care professionals – nurses, doctors, etc. – treating the patient;
- It strengthens the individuals' self-responsibility and feeling of being in control of his or her destiny which can significantly add to his or her quality of life, because the feeling of being 'at the mercy of the course of the illness' can be soothed;
- This strengthening of the individual in a difficult health situation also reduces the risk of desperate suicide attempts;
- And it therefore adds to a general positive development of public health

Obviously, these advantages can only unfold if Advance Directives are implemented in the law as a personal, legally enforceable instruction of an individual.

In Switzerland, the Swiss Civil Code article 370 ff made Advance Directives legally binding as of January 1st 2013.⁷ Some people use this option to express their wishes in regard of health care treatment they would like to receive or not in the future. It has brought about a positive development of strengthening the self-responsibility of individuals just as much as safety and clarity for loved ones and health care professionals.

4) Conclusion

DIGNITAS very much welcomes the discussion on the 'Draft National Health Amendment Bill'. It brings the issue of end-of-life-questions to the level where it should be addressed, the legislation.

For any question you may have, please do not hesitate to contact us; the board of DIGNITAS – To live with dignity – To die with dignity is happy to give oral evidence if members of Parliament would wish so. In the first week of September, a DIGNITAS-representative will be attending the 'World Federation of Right to Die Societies' biennial conference in Cape Town, where he can be met for a talk.

Yours sincerely

DIGNITAS
To live with dignity - To die with dignity



Ludwig A. Minelli



Silvan Luley

⁷ <https://www.admin.ch/opc/en/classified-compilation/19070042/index.html#a370>