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Forch, 27 February 2018

**End of Life Choice Bill,
Bill no 269-1, introduced by MP David Seymour**

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

for and on behalf of DIGNITAS' members in New Zealand
submitted in electronic format to ju@parliament.govt.nz
copy to MP David Seymour david.seymour@parliament.govt.nz

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1) Introductory notes

This submission is handed in by the non-profit member society DIGNITAS – To live with dignity – To die with dignity¹, for and on behalf of its members in New Zealand. The submission complements DIGNITAS’ submission of 30 January 2016 to the Health Select Committee’s “Investigation into ending one’s life in New Zealand, Petition no. 2014/18 of Hon Maryan Street and 8,974 others”. That earlier submission is publicly available online, both on the website of the New Zealand Parliament² and DIGNITAS³. The content of the submission of 30 January 2016 is to be considered an integral part of this submission now handed in. In line with the Guide “Making a Submission to a Parliamentary Select Committee”, the present submission focuses on specifically commenting the End of Life Choice Bill. In few places it refers to the previous submission by DIGNITAS and/or repeats parts of it.

DIGNITAS is happy to give oral evidence if the Committee would wish so. Due to the distance between Wellington and Forch-Zürich, this would be done preferably by video conference. Furthermore, members of the Justice Committee are welcome to visit DIGNITAS, such as Committees from Canada, England and Australia have done in inquiry stages of discussing how to implement assisted dying laws.

2) Terms used in this submission

When referring to the Swiss practice of a competent adult ending his or her own end of life with assistance of others, the term “assisting suicide / assisted suicide” in accordance with Swiss law⁴ is used in this submission. However, this term lacks indicating the important element of accompanying the process. With DIGNITAS, loved ones of the person wishing to end his or her suffering, and medical practitioners are involved in the process, accompanying the person through all the steps at his or her choice. For this reasons, DIGNITAS uses the term “accompanied suicide” in relation to enabling assisted suicide for its members.

When referring to the act of hastening death by administration of a lethal medication as foreseen in the End of Life Choice Bill, the term ‘assisted dying’ is used as defined in Part 1 of the End of Life Choice Bill.

3) DIGNITAS’ general position on the End of Life Choice Bill

DIGNITAS welcomes MP David Seymour’s initiative to table the End of Life Choice Bill and supports the measure. It brings the issue of end-of-life-questions to the level where it should be addressed: the legislation. There are only a few aspects of the Bill

¹ This the correct and full name; for easier reading, the short version “DIGNITAS” is used in this submission

² https://www.parliament.nz/en/pb/sc/submissions-and-advice/document/51SCHE_EVI_51DBHOH_PET63268_1_A485083/dignitas#RelatedAnchor

³ <http://www.dignitas.ch/images/stories/pdf/diginpublic/stellungnahme-investigation-into-ending-ones-life-in-nz-30012016.pdf>

⁴ See article 115 Swiss Criminal Code, <https://www.admin.ch/opc/en/classified-compilation/19370083/index.html#a115>

which DIGNITAS comments in chapter 5 of this submission. Where DIGNITAS does not comment, approval may be assumed.

4) Who is DIGNITAS and why does DIGNITAS write this submission?

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. In accordance with its articles of association, the objective of DIGNITAS is ensuring a life and a death with dignity for its members and of allowing other people to benefit from these values. DIGNITAS advocates, educates and supports for improving care and choice in life and at life's end, combining advice on palliative care, suicide attempt prevention, advance directives and assisted dying.

DIGNITAS' approach has always been 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 end his or her own life. In 2011, the European Court of Human Rights (ECtHR) confirmed this opinion in the judgment *HAAS v. Switzerland*, application no. 31322/07⁵ as it stated in paragraph 51:

”In the light of this jurisdiction, the Court finds that the right of an individual to decide how and when to end his life, provided that said individual was in a position to make up his own mind in that respect and to take the appropriate action, was one aspect of the right to respect for private life under Article 8 of the Convention”

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 self-determined end of life depends on domicile/residence and/or citizenship? The ECHR condemns such discrimination in article 14⁶. Therefore, the logic consequence for DIGNITAS was 1) to allow non-Swiss residents and non-Swiss citizens to access the possibility of an assisted suicide in Switzerland, which obviously includes New Zealanders, and 2) to advocate for implementation of “the last human right”, the practice of Switzerland, in other countries too. In its almost 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 and DIGNITAS has been consulted by committees, panels and representatives of parliaments, from England, Scotland, Sweden, Victoria-Australia, Canada and others, with an aim of implementing laws to introduce assisted dying, for example in the form of assisted/accompanied suicide as an additional end-of-life-choice.

Whilst it has to be acknowledged that the legal system in New Zealand permits for palliative care, in some cases if need be applied in the ultimate form of palliative continuous deep sedation, which provides an essential option of relief for the dying, the

⁵ Application no. 31322/07; Judgment of a Chamber of the First Section (in French): <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-102939>

⁶ http://www.echr.coe.int/Documents/Convention_ENG.pdf page 13

option of choosing a professionally supported self-enacted death, which is ending one's suffering in the frame of assisted/accompanied suicide, is not (yet) possible.

This leads to residents of New Zealand having to travel 18,771 kilometres (which is the air-line distance Wellington to Zürich) when all that he or she wishes is to have the choice of a dignified self-determined end of suffering.

The present legal situation in New Zealand has the additional appalling effect that the very important support towards the end of life by next-of-kin and friends must take place shadowed by the fear of prosecution. Sometimes, this even leads patients to decide to travel to DIGNITAS only with very few loved ones or even alone. The emotional and financial burden to the individual, their loved ones and society in general are problematic to say the least⁷.

In this context it should be pointed out that only individuals with at least a minimum of financial resources – something that certainly not everyone in New Zealand has – can afford to travel to Switzerland. DIGNITAS' articles of association / statutes allow for reduction or even total exemption of paying costs to DIGNITAS⁸, however, there are other costs to bear, which results in an unacceptable discrimination against those who are not financially well off.

Even if the journey to Switzerland can be funded, the person still would have to bear the burden of a long trip to a foreign country which is very strenuous given their deplorable state of health, and, what is even worse, they may have to travel earlier than they would wish for, compared to if they had the same option at home, in order to still be able to cope with the strain. In fact, this aspect of not giving suffering individuals a choice at home and such forcing them to 'having to go earlier' constitutes a violation of the basic human right to life and the principle of sanctity of life.

Clearly, the public is in favour of freedom of choice in these "last issues"⁹. No New Zealander should be forced to travel to Switzerland in order to have a self-determined, self-enacted, safe and accompanied ending of his or her suffering. Everyone should have access to such option at his or her home, as an additional choice besides palliative care measures (including palliative/continuous deep sedation), having treatment discontinued based on instruction through a personal health care advance directive, and the accompanying of dying individuals.

Today, DIGNITAS, together with its independent German partner association DIGNITAS-Germany in Hannover, counts 8,400 members worldwide of whom 16 reside in New Zealand. Since 2005, two New Zealanders have travelled to DIGNITAS for an

⁷ See the report "The True Costs - How the UK outsources death to DIGNITAS":

https://features.dignityindying.org.uk/true-cost-dignitas/?utm_source=homepage&utm_medium=homepage

⁸ http://www.dignitas.ch/index.php?option=com_content&view=article&id=11&Itemid=52&lang=en

⁹ See for example the Newshub Reid Research poll: <http://www.newshub.co.nz/home/politics/2018/02/newshub-poll-most-new-zealanders-support-euthanasia.html>, the Horizon Research report in July 2012 <http://www.horizonpoll.co.nz/attachments/docs/horizon-research-end-of-life-choices-survey--1.pdf>, the First Report of the UK Select Committee on Assisted Dying for the Terminally Ill Bill: <https://publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/8602.htm>, the ISOPUBLIC/GALLUP Poll http://www.medizinalrecht.org/wp-content/uploads/2013/03/Results_opinion_poll_self-determination_at_the_end_of_life.pdf and many more.

assisted suicide¹⁰. DIGNITAS writes this submission in the name of its New Zealand members, and for all other people who would like to have such freedom of choice now or in the future. The ultimate goal of DIGNITAS is to disappear: if people in New Zealand (and other countries) have the same choice as a Swiss resident in Switzerland, DIGNITAS will not be necessary for them anymore and then the DIGNITAS-association will become redundant.

The implementation of the End of Life Choice Bill in New Zealand would be an important step forward to more choice, care, and protection of life and dignity of suffering individuals.

5) Comments on the proposed End of Life Choice Bill

Ad Part 1, section 4 (a)

The End of Life Choice Bill (hereafter abbreviated “ELCB”) sets an age limit at 18 years. Even as this is the legal age in New Zealand, the following question should be considered: is a terminal cancer or a grievous and irremediable condition any different in a person of 19, 18 and 17 years of age? Provocatively said: is a 17-year-old New Zealander “less worthy” of being allowed access to a law (like the ELCB) which gives him or her choice and control over the final stretch of suffering, than an 18-year-old? Isn’t a 17-year-old, just as much as an 18-year-old individual capable of understanding the nature of assisted dying and the consequences for him or her (Part 1, section 4 (f)?

In this example, the condition set in section 4 (a) constitutes a discrimination against a 17-year-old individual. There are important reasons to allow “under-aged”, under certain conditions, access to assisted dying. These are, besides the legal aspects (avoiding discrimination, and respect for the basic human right to decide on time and manner of one’s own end in life¹¹), the elements of improving quality of life and moreover protection of life, most importantly through the suicide attempt preventive effect of having access to assisted dying. The Netherlands (from where the ELCB obviously draws some provisions, such as the SCENZ Group) and Belgium show that this can be put into practice legally, and work in practice.

Ad Part 1, section 4 (c) (i), (ii), (d) and (e)

The eligibility criterion “terminal illness that is likely to end [the person’s] life within 6 months” is possibly drawn from the Death with Dignity Act of the US State of Oregon¹², which served as a basis for laws in a few other US States such as Washington and California. The criterion terminal illness with a life expectancy of 6 months has several flaws: a) it discriminates against severely suffering competent New Zealanders who are not expected to die within 6 months, b) prognosis (not only) in medicine is difficult and thus not even the most competent medical practitioner would be

¹⁰ http://www.dignitas.ch/index.php?option=com_content&view=article&id=32&Itemid=72&lang=en

¹¹ See chapter 3 “The freedom to choose time and manner of one’s own end from a European Human Rights perspective” in the earlier submission of DIGNITAS.

¹² <http://www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx>

able to state with certainty whether his or her terminally ill patient is really going to be alive or not in 6 months – so it is just an estimate more or less basing on experience and, c) such fixed time window lacks the suicide-attempt-preventive effect that real access to choice has. The 6-month criterion is arbitrary, as it could be 8 months, 4 months or 12 months just as well. The ELCB should do without this criterion.

The discrimination mentioned in a) seems to be relativized by the ELCB in part 1, section 4 (c) (ii) as the section before says “or”, thus, “a grievous and irremediable medication condition” is an alternative, not a cumulative eligibility criterion. If this is the case, the 6-month terminally ill criterion as to (i) may as well be omitted. The criteria stated in (c) (ii), (d) and (e) already describe the situation of a patient with very poor health and a short life expectancy.

Overall, the eligibility frame set by the ELCB for assisted dying is rather narrow. The explanatory notes confirm this, stating it is an “option of relief to a small . . . number of people who suffer”. Besides, the ELCB lacks definitions of “unendurably” “grievous” and “irremediable”. The consequence of this frame is that an individual has to potentially decline far into an illness and experience severe suffering until he or she is considered to fall within the frame of the ELCB. This is inhumane. As already stated before as to the “6-month terminally ill” criterion, this constitutes a discrimination. One may argue that the name of the Bill speaks for itself: End of Life Choice. That is, choice (only) for individuals who are facing their end of life anyway. A law that intends to give suffering individuals choice, that intends to protect people from having to resort to a lonely, risky “do-it-yourself” suicide, or from having to go far away abroad to DIGNITAS – and that intends to improve New Zealanders’ quality of life and respecting human rights and dignity, should do better than restricting access to choice and relief from suffering only to people who are going to die in the short run. The latter is in no way meant cynically. It is to rethink one’s personal position and give some consideration to the aspect that in a democratic state it is not for the citizen to plead for access to freedom of choice, but it is for the state to justify restricting or not giving full access to it¹³. DIGNITAS invites the Justice Committee and MP David Seymour to have a close look at the Swiss model of assisted / accompanied suicide, which is a progressive, individual-orientated approach to caring for patients’ end-of-suffering requests, combining it with palliative care and suicide attempt prevention, taking into consideration personal self-determination, choice and self-responsibility. The earlier submission by DIGNITAS mentioned also offers a law proposal for New Zealand.

Ad Part 2, section 10 (2) (c) and section 11 (3) (c) (iii), in connection with section 12

As a principle, people who are of age have to be assumed to be mentally competent unless there are clear indications that their mental capacity is limited or no longer present, such as the person being delirious due to drugs or having hallucinations due to a psychiatric ailment¹⁴. This is set out in common law which recognises – as a

¹³ According to Professor AXEL TSCHENTSCHER at the University of Berne in Switzerland, „it is for the State to justify narrowing access to medication for assisted dying but not for the citizen to plea receiving access to it.”

¹⁴ See Swiss Civil Code article 16: <https://www.admin.ch/opc/en/classified-compilation/19070042/index.html#a16>

“long cherished right” – that all adults must be presumed to have capacity until the contrary is proved.

This assumption of competence is important in connection with these two sections. The current wording of the sections allows doctors to up front (in the worst case on purpose) declare the person who requests assisted dying to be incompetent and thus always trigger an assessment as to section 12. Of course, there may be situations that the attending and/or independent medical doctor has reasonable doubts as to the mental competence of the person requesting assisted dying. And for these situations, the provision in section 12, the assessment leading to the third opinion is the right way forward. However, the ELCB should state the common law assumption of competence and that only when there are clear signs of (potential) incompetence, the third opinion assessment would be necessary.

A side-note: when closely looking at the (legal) assumption of mental capacity, and the (medical) assessment of whether a person can be considered to be competent or not, one needs to remember that it is in fact impossible to “confirm” competence. It is only – but at least – possible to rule out signs / indicators / factors which would give a basis to consider a person being incompetent. In other words: mental competence cannot be confirmed, but ruling out signs of incompetence leads to the (legal) assumption that the person is competent. Therefore, the word “established” as to the two sections can only have the meaning in the sense described here.

One also needs to consider the problem of the common prejudice that people who wish for their life to end would be quite likely mentally incompetent. The same prejudice is all too often applied to people who suffer from a psychiatric illness. This prejudice leads to a labelling, stigmatising and belittling of these individuals. This prejudice needs to be overcome. No matter what the reasons are that a person wishes for his or her life to end, he or she should up front be taken serious and met as / taken for a rational competent individual. Only an approach of non-labelling and treating these individuals as “normal human beings in an extraordinary situation” will allow for an open-minded, open-outcome honest conversation a) about the reasons which brought the person to wish for his or her suffering and life to end and b) a joint search for possible solutions (of which assisted dying is just one amongst others). Of course, there are sometimes people reaching out for assisted dying who, from a medical point of view, may be found to be severely psychiatrically ill, acutely suicidal, in a deep crisis, potentially not mentally competent. But to start with, one should treat them the same way as everyone else: taking them seriously, listening, and not judging/labelling. People in declining health can feel helpless because they are unable to act alone. Their anger, grief and frustration grow due to the abilities they have lost or the possibilities that are unavailable. They may feel ashamed of not-being-able or not-being-capable anymore. Every prejudicial label has a negative effect as it nourishes these feelings. This must be avoided. Only an open-minded approach cracks the taboo surrounding the issue of end-of-life choices and suicide, and makes the person feel they are being taken seriously. Only if people feel respected and taken seriously (and certainly not labelled, belittled and shunned into the “mentally ill corner”), will they openly communicate and react rationally to input and support. This progressive

approach has maximum suicide attempt preventive effect and gives room to improving the quality of life of the person.

Ad Part 2, section 15 (3) (i) to (iv), in connection with section 16 (4) (a) and (b)

Whilst (i) and (ii) state “triggered by the person”, (iii) does not. The administration of a lethal dose of medication – at DIGNITAS, in all cases of assisted suicide 15 grams of Pentobarbital dissolved in plain tap water is used – through a tube can also be triggered by the person, just as much as the intravenous delivery (ii).

If we understand it correctly, the ELCB gives room for two different approaches to ingesting the medication: either the person performs the last act which brings about death himself or herself, which legally-technically is a suicide. Or the attending medical practitioner acts by injecting the medication (iv) on the person’s oft-repeated request, which legally-technically is voluntary euthanasia.

It is very important that the option of the medical practitioner acting on the person’s request is available. In Switzerland, unfortunately, this is not the case as only assisted suicide, under certain circumstances, is permitted. This has led to difficult situations for patients in a very deplorable state of health, especially with paralysis. It could always be resolved and, of course, always in line with the law. However, for the patients it would have been a huge relief if the medical practitioner could have administered the medication.

DIGNITAS’ experience matches the development in Canada which introduced medical aid in dying (MAID) after the Supreme Court decision in the Carter v. Canada case 6 February 2015. At the beginning, the discussion about putting assisted dying into practice revolved more around self-administering by the patient. It soon became clear that this was not sufficient, and administering of the medication by the medical practitioner was included in MAID. The administration by an experienced medical practitioner is an important element of safety for the patient: he or she is assured that despite his or her severe illness and incapability, access to relief under the ELCB is possible. Again, this is an important element for improving quality of life of the patient and, moreover, a suicide attempt preventive element.

As the ELCB points out in Part 3, section 19 (2) (g) (i) to (iii), it is the function of the SCENZ Group to work on this issue.

5) Conclusion

People of New Zealand should never again have to travel to DIGNITAS in Switzerland in order to make use of the basic human right of deciding on the time and manner of the end of his or her life. Or to resort to a “do-it-yourself” suicide involving a high risk of failure, trauma for third persons, and high costs to the public health sector.

The current legal status of assisted dying in New Zealand is indeed “inadequate and incoherent” as the UK Commission on Assisted Dying put it on the front of its final report¹⁵.

¹⁵ <http://www.demos.co.uk/project/the-commission-on-assisted-dying>

At a time in which lonely suicides among older people, in particular, are increasing – as a result of the significant increase in life expectancy and the associated health and social problems of many men and women who have become old, sick and lonely – careful and considered advice in matters concerning the voluntary ending of one’s own life is relevant. There are individuals who explicitly would like to add life to their years – not years to their life.

DIGNITAS calls on the politicians of New Zealand to take into consideration the aspects raised in this submission, and those pointed out in DIGNITAS’ earlier submission, and implement an improved End of Life Choice Bill which allows a competent individual to have a safe, dignified, self-determined and accompanied end of suffering and life at their own home – full choice on the time and manner of one’s end of suffering – which is in fact what a clear majority of New Zealanders wish for.

For any question the Committee 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 the Committee would wish so.

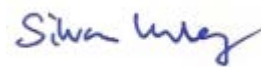
Yours sincerely

DIGNITAS

To live with dignity - To die with dignity



Ludwig A. Minelli
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