DIGNITAS
To live with dignity
To die with dignity

P.O. Box 17
8127 Forch, Switzerland
Phone +41 43 366 10 72
Fax +41 43 366 10 79
E-Mail: dignitas@dignitas.ch
Internet: www.dignitas.ch

Sender: P.O. Box 17, CH-8127 Forch
State Government of Victoria
Dept. of Health and Human Services
Continuing care
Health Service Programs
GPO BOX 4057
Melbourne VIC 3001
Australia

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# Consultation on the development of Victoria’s new end of life care framework

## Comments by DIGNITAS - To live with dignity - To die with dignity, Forch, Switzerland

submitted in electronic format,
by email to: EoLC.consultation@dhhs.vic.go

DIGNITAS is happy to give oral evidence if this is wished for

DIGNITAS very much welcomes the consultation ‘Improving end of life care’. Indeed, Victorians deserve the best possible and of life care, as MPs Jill Hennessy, Martin Foley and Gabrielle Williams put it in their ministerial foreword of the discussion paper.[1] And DIGNITAS could not agree more to as they put it, ‘They want to be with their family and friends and have the best possible quality of life for as long as possible’. Without doubt, this not only applies to Victorians, but all Australians and everyone around the world.

On 30 July 2015, DIGNITAS has already submitted a detailed answer to the ‘Inquiry into End of Life Choices - Are Victorian laws adequately meeting people’s expectations regarding medical options available at the end of their life?’.[2] In that earlier submission, several aspects of questions around end of life care have been dealt with. Therefore, we recommend that the committee of the now consultation on Improving end of life care refers to said earlier submission and we consider it as an integral part of the few notes submitted herewith.

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[1] http://betterendoflife.vic.gov.au/application/files/7914/4591/9517/1509023_Greater_say_for_victorians_WEB.pdf

[2] http://www.dignitas.ch/images/stories/pdf/diginpublic/stellungnahme-submission-inquiry-end-of-life-choices-victoria-30072015.pdf

Whilst the statements and questions within the five feature areas in the consultation paper cover the subject at hand very well, there are, however, two points which raise questions:

In ‘Key Feature area 1: enabling genuine choice’, the question to consider is ‘How do we ensure that people with a life-limiting illness are involved in, and have genuine choices, about decisions regarding their medical treatments and care for both current and future medical conditions?’ To DIGNITAS’ surprise, the consultation paper entirely excludes mentioning and/or raising questions on aspects of assisted dying in the sense of (physician-supported) assisted suicide as it is legal in Switzerland, the US-States of Oregon, California, etc., or voluntary euthanasia as legal in The Netherlands, Belgium and Luxembourg. Apparently, the consultation deliberately excludes assisted dying aspects from a debate on ‘end of life care’. This is a mistake.

Improving quality of life for severely suffering individuals facing life-limiting illness bases on taking serious the individual and his or her wishes and fears. Listening and taking serious is a central part of end of life care: only if those providing end of life care actually listen to the individual and talk about *all* aspects of end of life issues, they can provide the appropriate care – which is the care the patient wishes to have. This includes talking about the choice of ending one’s life self-determinedly, safely, at home and in the prescience of loved ones. A number of individuals – an indication of the number of people who would consider such option is, without doubt, the number of members with organisations such as Dying with Dignity Victoria[3] and others more – will entertain thoughts of putting an end to their suffering by own action and some will explicitly request for this.

Genuine choice is only possible with listening to, talking with and informing the individual. It is the same situation as with consenting to a medical treatment: such treatment, for example surgery, is generally only permitted if the patient has consented to it. And in order to consent, the patient needs to be informed and heard. A genuine choice on end-of-life care is only really ‘genuine’, if *all* options around end of life care are discussed in a professional, taboo-free and open-outcome manner. Therefore, in order to ensure that people with a life-limiting illness have genuine choice about decision regarding their medical treatments and care, those providing care also need to listen and talk about the issue of assisted dying if the individual raises the issue.

A second point which raises questions is the fourth paragraph on page 5 which says ‘Many people, whether through old age or at the end stage of chronic disease, cancer, dementia or a progressive neurological disorder, will have limited decision-making capacity for a period of time before they die and they may not

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[3] http://www.dwdv.org.au

be able to communicate their wishes or preferences for care'. This statement is too generalising. It lumps together illnesses which would typically lead to a gradual loss of capacity of discernment, such as dementia, with illnesses that have a devastating effect on the physical capacity but usually leave mental capacity untouched. In fact, it is precisely patients suffering from most forms of cancer and from progressive neurological disorders such as Motor Neurone Disease (ALS), etc. who find themselves becoming a 'functioning mind trapped in a non-functioning body'.

It is a common mistake to assume people who are stricken by a severe illness to have limited capacity of discernment or none at all. It is a prejudice. The same mistake happens in dealing with individuals who suffer from psychological problems and psychiatric illnesses. Such negative assumption, such 'limiting approach' to these individuals leads to up front labelling them as not being an adult, as not being a normal member of society, as not being someone who has the right to speak out for his or her wishes and to be respected. We need to remember that common law recognises – as a 'long cherished' right – that all adults must be presumed to have capacity until the contrary is proved.[4] Improving the wellbeing of an individual with a life-limiting illness has a lot to do with taking that individual seriously. Many severely suffering individuals just wish for 'a bit of normality' – so those providing end of life care, even more so those doing so professionally, should meet them as equals.

Improving care and choice in life and at life's end is about combining different approaches. This is why elements of palliative care, suicide attempt prevention, health care advance directives and assisted dying need to go together and need to be discussed, educated and made possible. Only if the full range of options which patients consider and wish for is available, one may call an end of life care system to offer genuine choice. Giving preference to one approach over another is depriving the individual of freedom of choice – which leads patients to take matters into their own hands such as trying to put an end to their suffering themselves, in short, to attempt suicide – with all its dire consequences of high risk of failure, being worse off than before the attempt and negative effects on third persons.

Yours sincerely

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Silvan Luley

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[4] Masterman-Lister v Brutton & Co [2003] 3 All ER 162, 169; L v Human Rights and Equal Opportunity Commission (2006) 233 ALR 432