

2013

Submission 1010

“I Have Questions to All Your Answers”

- *Woody Allen*

Final report on my study tour to undertake research into legislation, and the regulation and administration of euthanasia in Switzerland, the Kingdom of the Netherlands and Belgium

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Study Tour

Research into Legislation and the Regulation and Administration of Euthanasia in Switzerland, the Kingdom of the Netherlands and Belgium

Purpose

In June 2013 I undertook a study tour in order to research aspects of the law and practice in relation to end of life issues in three countries in Europe, that is Switzerland, the Kingdom of the Netherlands and Belgium, all of which have either legislated voluntary euthanasia or amended the penal code to allow assisted suicide.

In examining the different forms of legislation and codes I met with nearly 40 experts including members of the medical professionals, lawyers, ethicists, parliamentarians, policy makers and other stakeholders. I also undertook several site visits and examined the regulation and administration of the different models where they occur.

I was fortunate to also meet with palliative care practitioners and patients, those involved in developing and improving palliative care policy and advising Governments in this area.

I learnt about the long history of discussion and debate that has taken place in relation to end of life issues and the emerging debates in relation to calls to amend the legislation, particularly in Belgium. Also I looked at the role of palliative care in each country and the use of and validity of end of life directives, or Advanced Care Directives (ACD) - **E.g.** the role of medical practitioners in relation to ACD's.

I was motivated to undertake the study as members of the community raise end of life issues with me and the question of voluntary euthanasia, a choice that many in our community wish to have, is mentioned as their preference, if faced with prolonged unbearable suffering with no prospect of recovery.

Program

Switzerland

Monday, June 10

10. 00 am Meeting in Zürich, with General Prosecutor Mr Andreas Brunner.

2.00 pm Meeting with Mr Ludwig A Minelli, founder of DIGNITAS.

Tuesday June 11

10.00 am Meeting with Board Member of EXIT, Zürich, Mr Bernard Sutter.

4.30 pm Dr Ruth Burmann-Holzle Member of the Council of Ethics, met at Dialog Ethik, Interdisciplinary Institute Zurich.

Wednesday Jun 12

11.00 am Meetings at the Federal Office for Health, Berne with Dr Margaret Duetz Smicki, Senior Policy Advisor Palliative Care, Ms Michelle Novak National Strategy Palliative Care and Ms Lea von Wartburg Palliative Care Project, representing the Cantons, and Dr Steffen Eychmuller , Vice President Palliative Treatment, Switzerland.

Thursday June 13

Meeting with Mr Alexis Schmoker, Senior Policy Advisor to Vice Director of Federal Office of Justice, Berne.

Meeting with two MPs of High Chamber (similar to Federal Senate) who have tabled proposals in the matter, unfortunately these meetings were cancelled that day due to the 2 MPs being called away.

Friday June 14 Visit Swiss Parliament

Netherlands

Monday 17th June

4.30 pm Mrs Linda Voortman, Green Party Member of Dutch Lower House, The Hague.

Tuesday June 18th

Meetings with with the following Senators, all legal experts in the area of euthanasia, at Parliament House, The Hague.

- 10.30 am Senator Ruard Ganzevoort, Green Senator and Chair of Religion in Politics committee of his party.
- 2.00 pm sat in chamber for historic resignation speech of the then Chair (President) of Senate, first time such a resignation in the History of this Parliament.
- 3.30 pm Senator Heleen Dupuis, Liberal and Professor of Medical Ethics, and Senator Dr Tineke Slagter, Socialist Party, Member of Health Committee, GP and President of GPs Associatiin:
- 4.30 pm Senator Maria Martens Christian Democrate. Former Member of European Parliament.

Wednesday 19 June

10.00 am Dr Gert van Dijk Royal Dutch Medical Association "House of Medicine"
Mercatorlaan

3.00 pm Ms Dr Elise van Hoek- Burgerhart and Ms Charlotte Arieze-van Putten
MCS, members of NPV, Christian lobby organisation.

5.00 Wednesday 19 Ms Tellegen, new member of Dutch Parliament, The People's
Party for Freedom and Democracy, the Parliament at the Hague.

6.00 pm Dr Henk van Gerven, Member of Dutch Parliament for Socialist Party.

Thursday 20th June

10:30 to midday Nicole Visée, General Secretary to the Regional Review
Committees, The Hague.

1.00 pm, Dr J Hilbert Fleddéus and Mrs. (Hilbert) Fleddéus, L.LM, MSc., Ministry of
HWS , Ms Judith van den Berg H.D.K. Directorate Public Health Ethics section
Rijnstraat 50, The Hague.

3.00 pm Mrs. Keizer Member of Parliament for Christian Democrats Parliament
House, The Hague 0031621703427.

Friday 21 June

2.00 pm meeting with Dr de Wildt, advisor and assistant Reformed Political Party
Members of Lower House. Parliament House The Hague .
Tour of Parliament House, The Hague.

Belgium

Monday 24 June

10.00 am Meeting with Dr. Benoît Beuselinck Algemene Medische Oncologie
Supervisor of the General Oncology Service of the Universitair hospital of Leuven.

3.00 pm Meeting with Dr. Dominique Biarent Unité de Soins Intensifs Pédiatriques,
Head of the Intensive Care Unit at the Queen Fabiola Children's University Hospital,
Hôpital Universitaire des Enfants Reine Fabiola.

Tuesday 25 June

9.30 am Meeting with Ms Carine Brochier, European Institute for Bioethics.

5.00 pm Meeting with Michel Ghins, Professor of Philosophy at the Université Catholique de Louvain-la-Neuve.

Wednesday 26th June

11.00 am Meeting with Etienne Montero, Dean of the Law faculty of the University of Namur, and Virginie Niyonsaba (interpreter).

2.00 pm Visit of the Topaz Daycare Centre (Day Hospice) meeting with Ms Jacqueline Herremans and the rest of the team, and meet with day residents. Ms Jacqueline Herremans is a lawyer and President of the Association for the Right to Die with Dignity, and also meet Professor Distelmans, an expert in this field who works at Topaz, both sit on the Review Panel.

Thursday 27 June

11.00am Meeting with Senator Francis Delpérée at Senate:

1.00 pm Lunch with Senator Dirk Claes, Flemish Social Democrats, and Head of the Belgium-Australia parliamentary friendship group, at Senate.

2.30 pm Guided tour of the parliamentary precincts in English.

4.00 pm Meeting with Senator Philippe Mahoux, Francophone Socialists, former surgeon, a member of the Senate Commission for Justice and Social Affairs and a well known expert on the issue.

Friday 28 June

9.45 am Meeting with Senator Jacques Brotchi, Francophones Liberals, Senator and Professor of Neurosurgery, 67, Rue du Lombart.

2.00 pm Meeting with Professor Marc Englert, Retired Professor of Cardiology in his home.

Preliminary Findings

To do justice to this experience, or to try to pay full respect to those who shared their knowledge and expertise with me, is not possible in this brief report, however I hope to give readers a small snapshot of what I have learnt.

Switzerland:

In Switzerland there is no actual legislation which legalises voluntary euthanasia or assisted suicide, however under the Swiss Criminal code the penal code 115 says that it is not punishable by law to assist a person to commit suicide if the motivation to assist the person is not a 'selfish' one, ie. for the personal gain of a person or person's assisting, it must be seen as an 'act of a friend'. Other relevant Acts are the narcotics Act, last amended 1996, the Therapeutics Act and another relevant is the code of Ethics, **see appendix A**. The person who wishes to commit suicide must obtain a prescription from his general practitioner, a person who knows the patient and their medical history well. It must also be verified by a second doctor. (The prescription is held by the body which will "assist"). The patient must be able to make a 'conscious decision', not mentally impaired and not be suffering from clinical depression. All reports of assisted suicide go to the Coroner and the Public Prosecutor. To my knowledge there have been no prosecutions. The Chief Prosecutor told me that at first the assistance to commit suicide was only available to the severely ill, for example a person expected to die within two weeks, gradually this has come to include those who have impending death and those not necessarily terminally ill, for instance those "sick of life".

I was informed that, whilst the numbers of assisted suicides are growing they are not growing rapidly.

That is, in 2003 there were 1,400 suicides and 272 assisted suicides, i.e. 19.56% in 2009 the figures show 1105 suicides, 395 assisted suicides equalling 35.7%, 2010 there were 4445 assisted suicides, 576 in 2011 and 698 in 2012.

Organisations providing assisted suicide services in Switzerland:

Exit and Dignitas

There are 2 major organisations in Switzerland, and some smaller affiliated organisations, which provide assisted suicide services.

- Exit is a not for profit member based, and has a democratically elected board of governance and office holders, formed in 1982. Their booklet published in 2012 says they had 60,000 members at that point.
- Exit does not provide the service to non members and people who live overseas. They have based this decision on their belief that countries should introduce their own legalisation and shouldn't rely on Swiss services. The Board members I met also said they don't want to encourage "death tourism". Exit says that they do not to make a profit but do cover costs through membership and through people who donate or leave bequests.
- This website may be of interest :-
<http://www.worldrtd.net/sites/default/files/newsfiles/WF%20Newsletter%2061.pdf>
- Dignitas was set up in 1998 by Ludwig Minnelli, a former member of Exit who disagreed with the decision to not provide the service to persons from overseas. Dignitas now provides this service for overseas clients on a 'fee for service' which is a number of thousands of dollars, but it also offers assistance to those who cannot afford the full fee.

- People do not necessarily become a member of Dignitas in order to have an assisted suicide. I was told some sign up because they simply want to support the work. Others, especially in Switzerland, sign up in order to have our Patient's Instructions, (what we call an Advanced Care Plan).
- Figures as per December 2012 were 6595 members against 198 accompanied suicides, demonstrating that people do not join as a member just to have an assisted suicide.
- Dignitas report some people believe membership is like an insurance policy, in the sense of "knowing to be part of something where you can call upon if the worst comes to the worst. Also a central point: their work is not about "doing it" but about "having the possibility of doing it" and most of all having the possibility to talk about these issues, "it's something like an emergency exit door": "it's comforting to know it's there but you hope that you will never need it...."
- There are those (non-members and members) who ask Dignitas for information and advice, (I was told around one third of the daily "telephone work" is free-of-charge counselling work for people who are not even members).
- A smaller number than before decides to become a member. A smaller number again decides to send a formal request for the preparation of an accompanied suicide and a smaller number than that gets a "provisional green light"
- A smaller number still decides to see the Dignitas entirely independent Swiss physician who grants the "provisional green light" for a first consultation, and then an even smaller number than before decides to have the second consultation. Note: two consultations are mandatory.

- A smaller number again decides to set the date for the assisted suicide and to attend Dignitas that day; however they reported that a smaller number still actually takes the lethal medication.
- A research paper by a German student who undertook research in 2007, into 387 files of members of Dignitas and found that of those members who actually completed their formal request for an assisted suicide and who actually received a “provisional green light”, only some 14 % actually made use of an assisted suicide with Dignitas. The study is in German, however published on the English section of the website:
http://www.dignitas.ch/index.php?option=com_content&view=article&id=33&Itemid=73&lang=en
- The Swiss Association for the European Convention on Human Rights published figures in February 2011, on suicides for 2008, which showed assisted suicides are far fewer than those committed alone in that year, and more than 98% of those who attempted suicide were unsuccessful. i.e. more than 64.000 were unsuccessful, **appendix B.**

Netherlands:

In the Netherlands the law was introduced in 2002 to legalise euthanasia by a general practitioner, this occurred after many years of debate.

There are a number of criteria, it was stressed to me the most important of which are: to be able to make a conscious decision, to have unbearable suffering and no prospect of recovery.

The person's family general practitioner must be the person to make the decision based on the criteria and this must also be reviewed by an independent specially trained SCEN Doctor. The family GP may not be comfortable to carry out the procedure for religious or other reasons, so is not required to do so but should refer the person to a Doctor who will consider the request.

Nurses may not carry out the procedure, however can be present or and may be excused from being present. Once the euthanasia has been carried out the reports from both doctors go to the coroner and the cantons regional review committee. If a lawyer, doctor and ethicist detect any irregular reports they are referred to the public prosecutor.

Useful documents to refer to are FAQ Euthanasia 2010, The Termination of Life on Request and assisted Suicide (Review procedure) Act in practice, published by the Netherlands Ministry of Foreign Affairs, and the Knmg position paper, The role of the physician in voluntary termination of life, June 2011.

Belgium

In Belgium the legislation is very similar to the law in the Netherlands, introduced in 2002. Belgium legalises euthanasia on similar criteria, which again is approved by the family's general practitioner. I was told that if the family GP is unhappy to carry out the procedure, as in the Netherlands, the GP is morally obliged to refer on to another Doctor.

Again nurses are not obliged to be present if they do not want to be party to the procedure. The procedure can be carried out in the person's home with family present or just carried out by the family Doctor, at the person's request, with no one else present. The Doctor's decision to be able to approve and carry out euthanasia is also reviewed and verified by an independent Doctor, who is not the person's usual Doctor. Belgium has one review committee to which all reports must go, these reports must also go to the Coroner as well as the regional review committee. Again all irregular reports are referred to the Public Prosecutor.

It is interesting to note that there have been no prosecutions in any of the countries. The impetus for the introduction of the laws, to allow assisted suicide in Switzerland and euthanasia in the Netherlands and Belgium, grew out of a concern about people wanting to 'die with dignity', to have control over the way they die and to regulate "illegal acts" of assisted suicide and euthanasia which were believed to be being carried out in these countries anyway, under the radar (based on anonymous surveys of members of the medical profession).

I was informed that initially the introduction of this legislation was resisted by the political parties with strong Christian foundation, particularly Catholic. Note: Belgium is basically two countries in one, for example there is a Flemish speaking part, closest to the Netherlands, and the French speaking part which has a strong connection to France and the Catholic Church. There is also a small German speaking area.

Later the more conservative members of parliament backed the legislation which has strict criteria's and safeguards, but some conservative members tell me they are unhappy with regards to current moves to amend the laws to allow for greater access by groups not currently covered by the legislation.

Interestingly, I was told that 80% of euthanasia cases that are reported are from the Flemish speaking part of Belgium, with the other 20% reported from the French speaking cantons. However the population is roughly 65% Flemish and 35% French. Most cases of euthanasia are from people suffering from terminal cancer in all countries. It is therefore not reasonable to assume that less people in the French speaking cantons suffer from and are terminally ill with cancer. The reasons for the discrepancy have variously been proffered by those interviewed and appear to be based mostly on 2 factors:

- The Flemish speaking cantons are closer to the Netherlands and the practice is more 'familiar' and 'accepted' by medical practitioners and the public in those cantons.
- In the French speaking cantons medical professionals are often trained in French or Catholic institutions and practice in Catholic hospitals. There may be some "under reporting" by doctors who don't want to be identified as carrying out euthanasia by their peers and/or their hospital. There may also be some other methods being used to relieve severe symptoms such as pain, which leads to death occurring in a shorter time than perhaps would normally occur.

Other Options

Palliative care:

This does not seem to be well developed in Switzerland. I was told by a senior official in the Federal Swiss Health Department, Canton representatives and a palliative care senior executive, that the law allowing assisted suicide preceded resources being made available to develop better palliative care services. I was told that palliative care is still not embedded in the curriculum of the trainee doctors and nurses. The Federal Health Department and the cantons are working together on a Palliative Care Strategy at the moment, **appendix C**.

In the Netherlands and Belgium palliative care*, palliative treatment ** and hospice services exist side by side with the euthanasia legislation and regulation.

End of life advanced care directives and counselling

People in these three countries are encouraged to access counselling and to draw up their own end of life directives, advanced care plans. All people who are requesting assisted suicide or euthanasia must receive counselling and have all options explained to them. Switzerland reports that only a small percentage of people who actually make enquiries regarding assisted suicide finally 'go through with it'. In all countries I visited I was told that people believe that by having made arrangements to choose the time of their death and being enabled to do that, they can undergo treatment that possibly they would otherwise refuse because of the uncertain outcome, and believe it's an opportunity to "choose life".

Challenges

There were concerns expressed in all countries about movements gathering momentum to expand the criteria. For example the Chief Public Prosecutor in Switzerland said he would like the criteria to be more stringent, clearer and better defined, because “there are too many grey areas” and “it is too subjective”. In June 2011 an Assisted Suicide Report was produced in response to desire to achieve more objectivity and more explicated guidelines. The concern regarding needing clearer guidelines or more objectivity was also expressed by ethicists in all three countries and some politicians and lawyers.

Others want more freedom of choice for the individual to make his or her decision about his or her death and to have advanced care directives carry more weight. There are strong lobby groups, some with high profile members such as lawyers, writers and artists, who want euthanasia and assisted suicide to be allowed for younger people under 18 years, mentally ill, those with clinical depression, those diagnosed with Alzheimer’s and dementia and who have become unable to make informed decisions.

The equivalent to the AMA, The Royal Dutch Medical Association, advises their members that they don’t have to honour any “advanced care directives” which state that once “I no longer recognise my family, I am to be euthanized”. As when a person has reached that stage of Alzheimer’s or dementia the person will no longer be able to make a conscious decision, an important criteria, and it can’t be proven that the person is in unbearable suffering, another important criteria.

Online research undertaken by ISOPublic in 2012, into the views of Europeans in relation Assisted Suicide found 56 -78% can imagine considering assisted suicide when suffering serious illness, serious disability or uncontrollable pain. Also the same research shows 76-89% thinks that assisted suicide should only be realised by Doctors or trained practitioners.

It appears there is a growing body of thinking , , by people who say that one has the human right to have control over ones own body and therefore a Doctor should not refuse a request to assist, or at least must refer you to a Doctor who will. Still others, I was informed, claim no Doctor should be involved at all.

In the Netherlands I was told there is a relatively new “mobile service” through which one can access Doctors who will perform voluntary euthanasia, obviously adhering to the strict regulations and criteria

Other Concerns

Some parliamentarians and experts, such as lawyers and ethicists, that I spoke to, maintain that assisted suicide and euthanasia could become the “default” position unless the community and government don’t pay due attention to the human condition and our social responsibility.

They say that this is not a medical matter but a social matter. They strongly maintain that society must not let the most vulnerable in the community become more vulnerable, financially, physically, emotionally or mentally.

They cite examples of older or younger people who become isolated in the community through poverty, lack of access to work/ education or basic services, also people who face unpalatable choices or don't feel loved or cared for from their society or family.

Others suggested that the “popularity” or “acceptance” of these end of life options is creating a situation where people may feel ashamed or and may believe they have the moral responsibility to choose to die, and if they choose otherwise can be accused of “lacking courage”. However the strong counter argument, by those who have been involved in formulating legalisation and regulating these regimes for many years, is that people should be given the choice to end their life and not to have to endure a “bad death”.

Note

Palliative care and palliative treatment are seen as two different stages of a continuum in the Netherlands and Belgium. Palliative care* is seen as a service one can access quite early in the process, where one can access home based or day hospice based, counselling, remedial massage, physio, pain management, social events, skills development and a chance to consider end of life decisions. One oncologist describes this as “putting life into ones day not days into one's life”.

Palliative treatment** is seen as the treatment one receives in the last two weeks of life, usually heavily sedated to control pain.

The Swiss Palliative Care Association cites research undertaken by the Harvard University USA, in 2010, which showed that palliative care vs businesses as usual, for patients with advanced lung cancer, resulted in those who received the palliative care, living longer than expected, with better quality of life and costs the health dollar less. Those who choose to continue with their tertiary intervention die within the expected timeframe with less quality of life, according to the study, **appendix D p 3**.

Legalisation in Australia

As you know the last time a bill on euthanasia came into law in Australia in the N.T in 1995. However the Federal Parliament then passed the Euthanasia Laws Act 1997, also known as the Andrews Bill, which to prevent the Territories passing legislation allowing euthanasia. Under this legislation, the ACT, under the Self Government Act, is expressly forbidden from enacting such legislation.

The states are not prevented in the same way, evident through a move in NSW to introduce a euthanasia Bill which was recently passed in the lower house but not the upper house. Tasmania similarly has a bill on euthanasia which, when debated may pass through the lower house but it is not expected to survive the upper house.

There is still a good deal of research on this subject to be carried out in order to inform and be ready for community conversation. When asked, should access to euthanasia be allowed, 80% of the population say yes.

Meanwhile I believe a caring society always examines its responses to vulnerability in the community, in all its forms, such as financial stress, ill health, disability, isolation, relationships, and is aware of what people are asking for and why.

We must always say to ourselves “What are we doing to ensure that the vulnerable in our community are not becoming more vulnerable?” Of course one cannot legislate away suffering in our community as there is much that depends on how we respond to one another as a community.

Those who suffer from chronic disease, people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander peoples and financially and socially disadvantaged groups often suffer most when they face the end of life and have not had the support to plan for this time before it's too late.

What are we doing to address end of life issues? What are we doing to ensure that our palliative care, and palliative care environments, are well resourced and accessible? What are we doing to ensure our medical professionals, nurses and allied health workers are well informed and trained in the area of palliative care and end of life decisions?

What are we doing to inform our society about end of life challenges or how we can make sure we can make informed decisions which are respected? What are we doing to support a caring society and support our carers?

I was pleased to be able to attend an End of Life Issues and Decision Making Forum earlier this year, conducted by the ACT Local Hospital Network Council. The aim of the forum was to engage in a meaningful dialogue with the community and health clinicians to identify ways to improve the system for end of life care and decision making and assist the community and health clinicians to identify ways to improve the system for end of life care and decision making.

The forum was an extremely constructive event, and although many different opinions were shared, there was a strong consensus that everyone should be able to make decisions about their end of life care and should be supported by a system that respects their wishes.

At the completion of the forum, the Local Hospital Network Council made a number of recommendations:

- to increase community engagement and awareness about end of life care
- to increase community awareness of advance care planning
- to increase resources for advance care planning, including training of more staff
- to clarify the legal framework around advance care plans and create simpler legally binding tools to enable advance care planning
- to ensure advance care plans are easily available and systems act upon them, and
- to recognise the issue of futile care.

Work has already progressed on a number of these proposals and the report released recently sets the right direction for us to carry on this discussion.

Palliative care is an area that will experience a growth in demand as our population ages, and we need to respond to this challenge now so that people can receive the care and dignity they deserve at the end of their life.

I believe we need to talk about these issues so that we can provide palliative care in the most compassionate and dignified way possible. The ACT Government will shortly be releasing the *ACT Palliative Care Services Plan 2013-2017*.

I believe that this plan will incorporate strategies for new and emerging models of care in the provision of palliative services and will aim to create a more integrated, cohesive network of services across acute, community, and primary health care settings.

I very much appreciate the opportunity afforded me to undertake the study and to be able to meet and talk with so many compassionate and committed parliamentarians, professionals and practitioners. I would like to thank all those who assisted me by facilitating my visits and meetings.

In conclusion I would agree with the Woody Alan quote which hangs behind the door of Dr. Benoît Beuselinck, a research oncologist in a major hospital in Belgium, it says “I have questions to all your answers”.

The last entreaty of Professor Marc Englert, a retired cardiac specialist, who I visited on my last day in Belgium, was that I “must have courage”. By that I understood that one does need courage to continue to explore these questions of choice and support in relation to the end of life in a respectful, rational and compassionate way.

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Appendix A

311.0

Swiss Criminal Code

Book Two: Specific Provisions

Title One: Offences against Life and Limb

Art. 111

1. Homicide.
Intentional
homicide

Any person who kills a person intentionally, but without fulfilling the special requirements of the following articles, is liable to a custodial sentence⁶⁷ of not less than five years.

Art. 112⁶⁸

Murder

Where the offender acts in a particularly unscrupulous manner, in which the motive, the objective or the method of commission is particularly depraved, the penalty is a custodial sentence for life or a custodial sentence of not less than ten years.⁶⁹

Art. 113⁷⁰

Manslaughter

Where the offender acts in a state of extreme emotion that is excusable in the circumstances, or in a state of profound psychological stress, the penalty is a custodial sentence from one to ten years.⁷¹

Art. 114⁷²

Homicide at
the request of the
victim

Any person who for commendable motives, and in particular out of compassion for the victim, causes the death of a person at that person's own genuine and insistent request is liable to a custodial sentence not exceeding three years or to a monetary penalty⁷³.

Art. 115

Inciting and
assisting suicide

Any person who for selfish motives incites or assists another to commit or attempt to commit suicide is, if that other person thereafter

⁶⁷ Term in accordance with No II 1 para. 1 of the Federal Act of 13 Dec. 2002, in force since 1 Jan. 2007 (AS 2006 3459 3535; BBl 1999 1979). This amendment has been taken into account throughout the Second Book.

⁶⁸ Amended by No I of the Federal Act of 23 June 1989, in force since 1 Jan. 1990 (AS 1989 2449 2456; BBl 1985 II 1009).

⁶⁹ Penalties revised by No II 1 para. 16 of the Federal Act of 13 Dec. 2002, in force since 1 Jan. 2007 (AS 2006 3459 3535; BBl 1999 1979).

⁷⁰ Amended by No I of the Federal Act of 23 June 1989, in force since 1 Jan. 1990 (AS 1989 2449 2456; BBl 1985 II 1009).

⁷¹ Penalties revised by No II 1 para. 16 of the Federal Act of 13 Dec. 2002, in force since 1 Jan. 2007 (AS 2006 3459 3535; BBl 1999 1979).

⁷² Amended by No I of the Federal Act of 23 June 1989, in force since 1 Jan. 1990 (AS 1989 2449 2456; BBl 1985 II 1009).

⁷³ Term in accordance with No II 1 para. 2 of the Federal Act of 13 Dec. 2002, in force since 1 Jan. 2007 (AS 2006 3459 3535; BBl 1999 1979). This amendment has been taken into account throughout the Second Book.

commits or attempts to commit suicide, liable to a custodial sentence not exceeding five years or to a monetary penalty⁷⁴.

Art. 116⁷⁵

Infanticide

If a mother kills her child either during delivery or while she is under the influence of the effects of giving birth, she is liable to a custodial sentence not exceeding three years or to a monetary penalty.

Art. 117

Homicide through negligence

Any person who causes the death of another through negligence or recklessness is liable to a custodial sentence not exceeding three years or to a monetary penalty.

Art. 118⁷⁶

2. Abortion.
Illegal abortion

¹ Any person who terminates a pregnancy with the consent of the pregnant woman or incites or assists a pregnant woman to terminate her pregnancy without the requirements of Article 119 being fulfilled is liable to a custodial sentence not exceeding five years or to a monetary penalty.

² Any person who terminates a pregnancy without the consent of the pregnant woman is liable to a custodial sentence of from one⁷⁷ to ten years.

³ Any woman who has her pregnancy terminated or otherwise participates in the termination of her pregnancy following the end of the twelfth week since her last period and without the requirements of Article 119 being fulfilled is liable to a custodial sentence not exceeding three years or to a monetary penalty.

⁴ In cases falling under paragraphs 1 and 3 above, prescription takes effect after three years.⁷⁸

⁷⁴ Term in accordance with No II 1 para. 3 of the Federal Act of 13 Dec. 2002, in force since 1 Jan. 2007 (AS 2006 3459 3535; BBl 1999 1979). This amendment has been taken into account throughout the Second Book.

⁷⁵ Amended by No I of the Federal Act of 23 June 1989, in force since 1 Jan. 1990 (AS 1989 2449 2456; BBl 1985 II 1009).

⁷⁶ Amended by No I of the Federal Act of 23 March 2001 (Abortion), in force since 1 Oct. 2002 (AS 2002 2989 2992; BBl 1998 3005 5376).

⁷⁷ Term in accordance with No II 1 para. 4 of the Federal Act of 13 Dec. 2002, in force since 1 Jan. 2007 (AS 2006 3459 3535; BBl 1999 1979). This amendment has been taken into account throughout the Second Book.

⁷⁸ Amended by No I of the Federal Act of 22 March 2002 (Limitation of the Right to Prosecute), in force since 1 Oct. 2002 (AS 2002 2986 2988; BBl 2002 2673 1649).

Legal
abortion**Art. 119⁷⁹**

¹ The termination of a pregnancy is exempt from penalty in the event that the termination is, in the judgment of a physician, necessary in order to be able to prevent the pregnant woman from sustaining serious physical injury or serious psychological distress. The risk must be greater the more advanced the pregnancy is.

² The termination of a pregnancy is likewise exempt from penalty if, at the written request of a pregnant woman, who claims that she is in a state of distress, it is performed within twelve weeks of the start of the pregnant woman's last period by a physician who is licensed to practise his profession. The physician must have a detailed consultation with the woman prior to the termination and provide her with appropriate counselling.

³ If the woman is incapable of judgement, the consent of her legal representative is required.

⁴ The cantons designate the medical practices and hospitals that fulfil the requirements for the professional conduct of procedures to terminate pregnancy and for the provision of counselling.

⁵ An abortion is reported for statistical purposes to the competent health authority, whereby the anonymity of the woman concerned is guaranteed and medical confidentiality is preserved.

Art. 120⁸⁰Contraventions
by physicians

¹ Any physician who terminates a pregnancy in terms of Article 119 paragraph 2 and who fails, prior to the procedure:

- a. to obtain a written request from the pregnant woman;
- b. to discuss the termination in detail with the pregnant woman and to counsel her, to advise her of the risks of the procedure to her health, and to provide her with a written guide, the receipt of which she must acknowledge with her signature, that contains:
 1. a list of agencies that provide counselling free of charge,
 2. a list of associations and agencies that offer moral and material support, and
 3. information on the possibility of having the child adopted;
- c. to satisfy himself that a pregnant woman under 16 years of age has been in contact with a counselling agency specialised in dealing with young people.

⁷⁹ Amended by No I of the Federal Act of 23 March 2001 (Abortion), in force since 1 Oct. 2002 (AS 2002 2989 2992; BBl 1998 3005 5376).

⁸⁰ Amended by No I of the Federal Act of 23 March 2001 (Abortion), in force since 1 Oct. 2002 (AS 2002 2989 2992; BBl 1998 3005 5376).



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The various forms of euthanasia and their position in law

Go to page «Euthanasia»

Direct, active euthanasia

Deliberate killing in order to shorten the suffering of another person. The doctor or a third party deliberately administers an injection to the patient which results directly in their death.

At present, this form of euthanasia is punishable under Article 111 (murder), Article 114 (mercy killing on request) or Article 113 (manslaughter) of the Swiss Penal Code.

Indirect, active euthanasia

Defined as the use of means to relieve suffering (e.g. morphine) which may have the secondary effect of shortening life. The possibility that death might occur earlier than it would otherwise have done is taken into account.

While not covered explicitly by the penal code, this type of euthanasia is generally regarded as permissible. This perspective is also reflected in the euthanasia guidelines of the Swiss Academy of Medical Sciences (SAMS guidelines).

Passive euthanasia

The renunciation or discontinuation of life-prolonging measures. (Example: A life-support machine is switched off.)

There are no specific legal provisions governing this form of euthanasia, either, although it is regarded as permitted. The SAMS guidelines also define passive euthanasia in the same terms.

Assisted suicide

According to Article 115 of the Swiss Penal Code, only a person motivated by self-serving ends who helps another to commit suicide (e.g. by obtaining a lethal substance) will be punished by imprisonment for up to five years, or by pecuniary penalty.

Assisted suicide involves enabling the patient to obtain the lethal substance, which the person wishing to commit suicide then takes themselves without any external assistance.

Organizations such as EXIT offer assisted suicide within the framework of the law. Provided they cannot be accused of having any self-serving motive they are not punishable.

According to the SAMS guidelines, assisted suicide "is not part of a physician's activity".

Palliative medical treatment and care

Palliative medicine and care describes not only medical treatment and physical care, but also psychological, social and pastoral support to the patient and their family.

It can significantly increase the quality of life of the seriously and terminally ill and thus also avoid a situation in which they express the wish to die.

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Euthanasia: Enforcing applicable law

Federal Council acknowledges euthanasia report

Press Release, FDJP, 31.05.2006

Bern. Wednesday saw the Federal Council acknowledge the "Euthanasia and Palliative Care – Does the Confederation Need to Act?" (Sterbehilfe und Palliativmedizin – Handlungsbedarf für den Bund?) report, which clarifies a number of issues raised by a motion put forward by the Council of State's Committee for Legal Affairs. The report concludes that possible abuses of assisted suicide must be prevented by the consistent application and enforcement of applicable law, especially by the criminal prosecution authorities. It also stated that, in principle, no further legislation is necessary in the area of euthanasia. Further to a report by the Federal Department of Justice and Police (FDJP), the Federal Council is recommending that the Swiss parliament should not pursue a revision of the relevant provisions of the Penal Code and should not enact any new legislation on the authorization and supervision of assisted suicide organizations.

The FDJP report comes to the following conclusions:

The Swiss Penal Code (Strafgesetzbuch, StGB) does not contain any explicit provisions governing passive euthanasia (not taking or discontinuing action to prolong life) and indirect active euthanasia (administering pain relief, the side effect of which is to shorten life). The Penal Code does, however, prohibit killing for any reason, thereby drawing a clear line between punishable and non-punishable acts that is comprehensible to both medical practitioners and the criminal prosecution authorities. Legislators could include more specific provisions in the StGB or in another law, stating the circumstances under which these two forms of euthanasia would not be punishable acts. However, any general statutory ruling would still fail to address the critical questions that are raised in each individual case, and would therefore be of no practical benefit. Professional codes of practice, meanwhile – such as the guidelines issued by the Swiss Academy of Medical Sciences – are better suited to dealing in detail with the manifold complexities of such cases.

Palliative care, which refers to all aspects of the support and care of terminally ill patients, helps to reduce the numbers of those requesting assisted suicide or active euthanasia. Palliative care allows these people to live out the last stage of their lives in dignity and to die with dignity. The report states that it is possible, indeed necessary, to expand the range of palliative care on offer and to improve information and advice to those concerned and their families. Palliative care falls largely within the authority of the cantons, while the Confederation might institute supporting programmes in the areas of training, research and the funding of care.

Assisted suicide is permitted in Switzerland if it is not motivated by self-interest. This liberal approach has permitted the establishment of assisted suicide, or "right-to-die", organizations and led to the phenomenon of "suicide tourism". The increase in organized assisted suicide brings with it a danger of crossing the line between legal and punishable action. Abuses can nonetheless be prevented by the consistent application and enforcement of applicable law at both cantonal and municipal levels.

The Confederation could also enact supervisory legislation to monitor assisted suicides, but the options that have been examined have proven excessive and unworkable. They would tie the process up in red tape and make it difficult for the state to authorize assisted suicide organizations.

Further work

The anaesthetic sodium pentobarbital is widely used in the suicides assisted by right-to-die organizations. It may be that the conditions for prescribing and administering sodium pentobarbital are made more restrictive in future, thereby preventing abuse. In a second step, the Federal Council will look into a possible revision of anaesthesia legislation and measures to promote palliative care.

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Regulations on prescribing and issuing sodium pentobarbital are sufficient

Federal Council acknowledges supplementary report on euthanasia

Press Release, FDJP, 29.08.2007

Berne. Regulations governing the prescribing and issue of the anaesthetic sodium pentobarbital are sufficient. Swiss drugs legislation does not require any stricter rules to prevent possible abuses in cases of assisted suicide. That is the conclusion reached by the supplementary report on euthanasia that the Federal Council acknowledged on Wednesday.

Assisted suicides involve risks of abuse on several fronts. There may be pressure, coercion, threats or deception by third parties, or the person concerned may not be capable in legal terms of making the associated decisions. Cases like these result not in a suicide, but in a homicide. The person assisting the suicide may also be motivated by self-interest. The Federal Department of Justice and Police (FDJP) therefore joined forces with the Federal Department of Home Affairs (FDHA) to examine whether or not the prescribing and issue of lethal doses of sodium pentobarbital might be made subject to stricter requirements through a revision of Switzerland's drugs legislation. All of the options that were reviewed proved unviable, however.

- The doctor could be required by law to investigate the patient's state of health and desire to die in depth or on several different occasions and, where necessary, to bring in further specialists. This would nonetheless contradict the principle that the prescribing and issue of medical drugs is not governed in detail in the statute books, but should instead observe recognised rules of medical science.
- Sodium pentobarbital might be issued exclusively to assisted suicide organisations, to prevent the use of any residual amounts by third parties, for example. However, this approach would not offer any guarantee that these organisations would properly and effectively carry out the role they had been given.
- Sodium pentobarbital might be reclassified under secondary drugs legislation. This would simply result in deliveries of the drug having to be reported (i.e. an ex-post check), and would therefore not be able to prevent abuse.
- While the sodium pentobarbital was being administered, doctors might be obliged to monitor whether the patient was committing suicide of their own free will or being killed by a third party. Such "policing" duties are not part of the doctor's remit, however.

Action under supervisory law in the event of a breach of duty

The supplementary report emphasises that the present statutory provisions and codes of conduct are sufficient, and compliance with them is monitored by the competent cantonal supervisory bodies. If a doctor fails to fulfil their duty (e.g. by not examining a patient thoroughly), the supervisory authority will take the necessary action, which might extend to the withdrawal of the doctor's licence to practise. Furthermore, the cantonal prosecuting authorities will instigate the necessary steps if a criminal act is suspected.

Strengthen research into palliative care

The supplementary report also provides a summary of the action that has been taken to date and has been planned for the future to promote palliative solutions. In addition, the FDHA will submit

proposals to the Federal Council on strengthening research into palliative care.

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Organised assisted suicide to be regulated

Federal Council presents two options for consultation

Press Release, FDJP, 28.10.2009

Berne. The Federal Council wishes to lay down specific regulations for organised assisted suicide. It is proposing two options that will change Swiss criminal law: the determination in the Penal Code of clear duties of care for employees of assisted suicide organisations, or a complete ban on organised assisted suicide per se. On Wednesday, the Federal Council presented the two versions of its bill, as well as an explanatory report, for consultations that will last until 1 March 2010.

Essentially, the Federal Council does not wish to take anything away from the current, liberal legislation, which permits someone to assist a suicide provided they are not motivated by their own interests. However, since assisted suicide organisations are increasingly testing the boundaries of the law, and in some cases evading state and professional monitoring mechanisms, the Federal Council sees an urgent need to lay down guidelines and restrictions. These should prevent organised assisted suicide becoming a profit-driven business. They should also ensure that assisted suicide is available to terminally ill patients only, remaining closed to those with a chronic or mental illness. Suicide can only be the very last resort. The Federal Council believes in the paramount importance of protecting human life. Specifically, it wishes to promote palliative care and suicide prevention to offer suicidal individuals alternatives to taking their own life.

Option 1: Strict duties of care

The bill preferred by the Federal Council would amend Article 115 of the Swiss Penal Code (Strafgesetzbuch) and the identical Article 149 of the Military Penal Code (Militärstrafgesetz) to include a number of duties of care. The following elements are significant in this regard:

Free and lasting will

Under the new regulations, in a specific case of assisted suicide, employees of assisted suicide organisations would be committing a criminal offence unless it can be proven that they have observed all of the duties of care laid down in the Penal Code. First of all, the suicidal person must freely declare their wish to die, and must have given long and proper consideration to their decision. This provision is intended to prevent impetuous decisions that have not been thought through.

Two doctor's certificates required

In addition, the person who wishes to die must present two certificates from two different doctors who are independent of the assisted suicide organisation. One of the certificates must attest that the suicidal person has the legal capacity to decide for themselves; the second must state that the suicidal person suffers from a physical illness that is incurable and will result in death within a short period. This would rule out organised assisted suicide for those with chronic illnesses that are not in themselves terminal, and for those suffering mental illness. Comprehensive treatment, care and support, in the sense of palliative medicine, should allow these people to continue to live in dignity.

No commercial purpose

Furthermore, those assisting a suicide must discuss and examine alternatives to suicide with the

person concerned. The drug that is used must have been prescribed by a doctor. This demands that a diagnosis and the corresponding indications be established in accordance with the physician's professional obligations and duties of care. Those assisting a suicide may not be pursuing commercial ends. They may not accept any payment for their services that would exceed the costs and expenses of the assisted suicide. This provision ensures that those assisting a suicide are not driven by personal gain, and that their prime motivation is to help the person who wishes to die. Finally, the assisted suicide organisation and those who actually assisted the suicide must document each case comprehensively in order to help any enquiries on the part of the criminal prosecution authorities.

The Federal Council firmly believes that, by determining these duties of care, the negative aspects and abuse of organised assisted suicide can be prevented, and "suicide tourism" can be reduced.

Option 2: Ban on organised assisted suicide

As an alternative to more restrictive legislation, the Federal Council has also tabled a complete ban on organised assisted suicide for debate by the Swiss parliament. This option rests on the belief that individuals working in assisted suicide organisations are never actually motivated by purely altruistic reasons, and may develop a close relationship with the suicidal person.

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Assisted suicide: strengthening the right of self-determination

The Federal Council continues to support suicide prevention and palliative care

Press Release, The Federal Council, 29.06.2011

Berne. On Wednesday, the Federal Council decided against introducing specific provisions in criminal law on organised assisted suicide. It concluded that such an amendment to criminal law would have various drawbacks. However, the government is still intent on fostering suicide prevention and palliative care in order to reduce the number of suicides. The entire package of measures should contribute to strengthening the right of self-determination.

In response to the outcome of the consultation process, the Federal Council instructed the Federal Department of Justice and Police (FDJP) on 17 September 2010 to revise the proposed definition of due diligence for employees of assisted suicide organisations. Today, the Federal Council concluded that such a revision would only specify in detail the obligations which already arise from the prevailing law (Article 115 of the Swiss Criminal Code and Article 119 of the Military Criminal Code); to render assisted suicide admissible, the current legal provisions already require the person seeking suicide to have the mental capacity to consent and to be sufficiently well informed. Moreover, the term "selfish motives" referred to in the abovementioned legislation already renders criminal prosecution possible in cases of assisted suicide abuse.

Indeed, revising current legislation could have various drawbacks. One such argument is that it could officially legitimise assisted suicide organisations, which could provide people with an incentive to take up their services. This legitimisation could give the impression that some lives are worth protecting, while others are not, thus compromising the sanctity of human life. Furthermore, a change in legislation would not be well accepted particularly by doctors whose professional body during the consultation process came out against making medical practice out of assisted suicide. Instead, the medical association argued that the prescription of lethal substances should remain the personal responsibility of the individual doctor.

After reviewing the situation once again, the Federal Council is convinced that misuse of the system – such as the assisted suicide of people who do not have the mental capacity to consent, the dispensing of pentobarbital sodium without a doctor's prescription or the illegal storage thereof – can be tackled under the current legal provisions. The current criminal law provisions, the Therapeutic Products Act, the Narcotics Act and conduct rules together provide the authorities with a suitable set of tools for imposing effective criminal, administrative or civil law sanctions. Moreover, these tools have the advantage of being flexible and practice-oriented as well as constituting a sensible balance between the State's responsibility to protect the individual and to respect personal freedom.

Improving self-determination at the end of life

The Federal Council continues to give priority to preventing suicide. The number of annual suicides, which has remained constant in Switzerland for several years, is expected to increase in the future as the population ages. For this reason the Federal Council wishes to continue to support the prevention of suicide, palliative care, and the care and treatment of people with terminal, life-threatening and chronic illnesses. The focus is on improving self-determination at the end of life. To this end, the public should be made aware of the alternatives to suicide.

The Federal Council has instructed the Federal Department of Home Affairs (FDHA) to review the extension of the National Strategy for Palliative Care, which is due to expire at the end of 2012. The FDHA will also continue to support the cantons in launching a programme called Bündnis gegen Depression ("Anti-depression Alliance") for the early diagnosis and optimal treatment of depression. Finally, the FDHA will establish an interdepartmental working group whose task will be to propose measures for improving the compatibility of work and care of terminally ill dependants (for example, granting leave from work to care for sick relatives or care vouchers).

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Specific regulations for organised assisted suicide in Switzerland

Swiss Federal Council acknowledges results of consultation process

Press Release, FDJP, 17.09.2010

Bern. During the recent consultation process, a clear majority of cantons, political parties and interested organisations spoke out in favour of specific, federal-level regulations for organised assisted suicide. On Friday, the Federal Council instructed the Federal Department of Justice and Police (FDJP) to revise the proposed setting of duties of care for employees of assisted suicide organisations in response to the outcome of the consultation process. The FDJP will draft a Federal Council Dispatch on the matter by the end of 2010. The Federal Department of Home Affairs will present its proposals for strengthening suicide prevention and palliative care at the same time.

Present federal and cantonal control mechanisms are not tough enough. The Federal Council thus believes there is an urgent need for new guidelines and restrictions. Last autumn, the Council opened consultation proceedings on two alternative amendments to criminal law: the setting of strict duties of care for employees of assisted suicide organisations, or a complete ban on organised assisted suicide. The need for legislative action was supported by 22 cantons, 8 political parties and 54 organisations. Just 4 cantons, 5 parties and 16 organisations took the view that current legislation is sufficient to prevent abuse.

No consensus

Although a clear majority believes in the need for action at federal level, there is still no consensus about how exactly organised assisted suicide should be governed. Some 35 participants in the consultation process advocated the setting of strict duties of care (option 1), while 20 spoke out in favour of a complete ban on organised assisted suicide (option 2) and 22 called for a special law on the matter. Option 1 was criticised as too complex and opaque. Furthermore, the provision which would make organised assisted suicide the preserve of terminally ill patients was described as discriminatory and unlawful. There were also reservations with regard to the provision that would make it mandatory for three doctors to be involved in the assisted suicide, specifically to confirm the patient's legal capacity and their terminal illness, and to prescribe the anaesthetic sodium pentobarbital. Specifically, option 2 was accused of being an unlawful restriction on the right to self-determination.

Some participants in the consultation process preferred that a special law be drafted to govern the activities of assisted suicide organisations. They proposed, for example, that assisted suicide organisations be subject to licensing, or that a medical or official supervisory authority be set up. In their position papers, a large number of participants also called upon the Federal Council to lend greater support to suicide prevention and palliative medicine.

Determining duties of care

Three quarters of those who took part in the consultation process believe that legislative action is required. The Federal Council remains firm in its intention to govern organised assisted suicide expressly under the provisions of criminal law. Based on option 1, it will draft a bill for debate by the Swiss parliament. In doing so, the FDJP will engage the services of external experts, and will take into consideration the criticism voiced during consultations. The Federal Department of Home Affairs will also submit proposals to the Federal Council on how suicide prevention and palliative

care can be strengthened.

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Appendix B

FAILED SUICIDE ATTEMPTS, SUICIDE AND «VOLUNTARY PARTINGS» IN SWITZERLAND

Figures of the year 2008

Voluntary partings with

DIGNITAS 131



This is the media's favourite hype

EXIT 167 (Swiss-German Section 179, Swiss-French Section 66)

Suicides
1.313

Yet, where would politics really be needed?

one every six-and-a-half hours, this is between 3 and 4 daily

Failed Suicide Attempts

up to 64.337

one every 8 minutes 11 seconds

or seven to eight in one hour

or 176 in a single day

or 1.232 in one week

or 5.361 in one month

total costs of 2.4 billion Swiss Francs every year

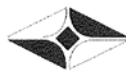
in one day this is 6.575.342 Swiss Francs

this is 4.566 Swiss Francs every minute

Appendix C



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GDK Schweizerische Konferenz der kantonalen Gesundheitsdirektorinnen und -direktoren
CDS Conférence suisse des directrices et directeurs cantonaux de la santé
CDS Conferenza Svizzera delle direttrici e dei direttori cantonali della sanità

Summary

National Strategy for Palliative Care 2013-2015

Results 2010-2012 and
need for action 2013-2015



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Major Objective of the National Strategy for Palliative Care

The Confederation and cantons will collaborate with the most important actors in the field of public health and in other areas to integrate palliative care. This will allow all critically ill and dying people in Switzerland to receive palliative care that is adapted to their needs in order to improve their quality of life.

1 Initial Situation

On 25 October 2012 the «Dialogue on national health policy», the common platform of the Confederation and the cantons, adopted the «National Strategy for Palliative Care 2013–2015». The «National Strategy for Palliative Care 2010–2012» was thus extended for another three years.

Throughout the course of the initial strategy, many measures were implemented in the past three years in the six sub-projects "Care", "Financing", "Awareness", "Training", "Research" and "Interdisciplinary sub-project". However, the main objective cited above was not completely achieved. The broad implementation of the established principles still needs to be completed in many areas. The period of three years determined for implementing the measures defined in the strategy was too short based on the available personnel and financial resources.

This summary of the "National Strategy for Palliative Care 2013-2015" presents the overall results in the six sub-projects of the "National Strategy for Palliative Care 2010-2012". The action needs, the objectives and measures for progressing the 2013-2015 strategy in the various areas will also be laid out.

1.1 Palliative Care

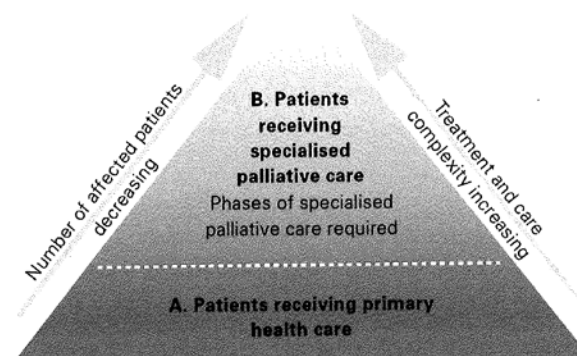
According to the "National Guidelines for Palliative Care", palliative care comprises "the care and the treatment of persons with incurable, life-threatening and/or chronically progressive illnesses". It is proactively taken into account, but its focus is on the time when the cure of the disease is no longer considered possible and no longer represents the primary objective. Patients are guaranteed an optimal quality of life depending on their situation until they pass away, and closely related persons receive adequate support. Palliative care prevents suffering and complications. It includes medical treatments, nursing interventions as well as psychological, social and spiritual support.¹

The 4th guideline "Target Groups" stipulates that palliative care focuses on the needs, symptoms and problems of patients as well as their relatives and friends. Because of their different needs, a distinction is made between patients receiving primary palliative care (patient group A) and patients receiving specialised palliative care (patient group B) (see Fig. 1). Primary care in this case is understood as long-term care, acute hospital care as well as out-patient care provided by GPs or primary care teams as well as other health professions.²

¹ Federal Office of Public Health (FOPH) and Swiss Conference of the Cantonal Ministers of Public Health (CMH) (2010) National Guidelines for Palliative Care

² Practising physicians with a postgraduate title General Medicine, Internal Medicine and General Internal Medicine, Paediatric and Adolescent Medicine as well as practising physicians with General Medicine as the sole postgraduate title are designated as the primary care physicians. Additional health professions include qualified nurses, pharmacists, midwives, qualified physiotherapists and occupational therapists, dieticians as well as assistant professions such as medical assistants or health specialists. cf. Swiss Conference of the Cantonal Ministers of Public Health (CMH) and Federal Office of Public Health (FOPH) (2012): New models for care in medical primary care. Report of the working group "New models for care in medical primary care" by CMH and FOPH p. 5

Fig. 1: Target groups for palliative care



Source: FOPH and CMH (2010): National Guidelines for Palliative Care

The transition between these two groups is fluid. This means that patients may belong to both groups over the course of their illness. Because a sick person may temporarily be doing better, the phases of instability and complexity of group B alternate with phases of group A.

1.2 Palliative Care in Switzerland:

The need for palliative care will increase significantly in the coming years. The present age distribution of the Swiss population in the long term will lead to an ageing of society.³ The 'average' scenario of the Federal Statistical Office (FSO) predicts that the percentage of those aged 65 and above in the population will increase from 17 per cent in 2010 to 28 per cent in 2060.⁴ The demographic development involves an increase in the number of old people who will require nursing care. The health care system must prepare itself for the fact that medical treatment and care during the last phase of a person's life will become more complex.

At the same time, due to the changed age distribution, the annual number of deaths will also increase: at present in Switzerland there are about 60 000 deaths each year for all ages. Current scenarios for the demographic development estimate a significant increase in deaths for the coming years. Thus, the FSO predicts a one third increase in the number of deaths within the next 20 years, i.e. rising from 60 000 to 80 000 people per year.⁵

The number of palliative care patients will most likely also increase along with the predicted increase of annual deaths. On the basis of today's figure of 40 000 people per year who require palliative care (estimate from international studies), this number should rise to the order of 53 000 people over the next 20 years. This increase will have a major impact in the area of primary palliative care:

³ Swiss Federal Statistical Office (SFSO): Future population development – data, indicators – Switzerland, scenarios. <http://www.bfs.admin.ch/bfs/portal/de/index/themen/01/03/blank/key/intro.html> (accessed April 2012)

⁴ The SFSO has recently issued three base scenarios for the future development of the population in Switzerland: the "low", the "average" and the "high" scenario. Here, the "average" scenario is taken as the reference scenario. This scenario is based on the continuation of the developments of the last years, SFSO (2010): Scenarios for the Development of the Population in Switzerland 2010–2060. Neuchâtel, p. 5

⁵ Swiss Federal Statistical Office (SFSO): Future population development – data, indicators – Switzerland, scenarios. <http://www.bfs.admin.ch/bfs/portal/de/index/themen/01/03/blank/key/intro.html> (accessed April 2012)

	2012	2032
Total deaths in Switzerland	60'000	80'000
Total number of palliative care patients (estimate: two thirds)	40'000	53'000
Of which patients needing primary palliative care (estimate: 80%)	32'000	42'000
patients needing specialised palliative care (estimate: 20%)	8'000	11'000

Table 1: Number of palliative patients in Switzerland in 2012 and 2032 (estimation)

In view of the demands for a strengthened integrated medical care of the population and for reduced healthcare costs, the promotion of palliative care corresponds with the direction of the strategic health policy of the Confederation and cantons.

2 Results of the “National Strategy for Palliative Care 2010-2012”

The implementation of the measures began in January 2010 in the six sub-projects «care», «financing», «awareness», «education and training», «research» and «interdisciplinary sub-project». The overall direction of the strategy rests with the Federal Office of Public Health FOPH. The joint management of the sub-projects included representatives from the Swiss Conference of the Cantonal Ministers of Public Health CMH (care and financing), the Federal Office for Professional Education and Technology OPET (education and training), the Federal Statistical Office FSO (research) as well as the Swiss Association for Palliative Medicine, Care and Support «palliative ch» (care, awareness).

Most of the measures of the strategy phase 2010 to 2012 involved the preparation of broadly agreed basic principles in the field of palliative care – both in regard to the definition, as well as relating to the areas of care structures, quality, training, awareness raising, financing or research.

2.1 Interdisciplinary sub-project

- **National Guidelines for Palliative Care** The “National Guidelines for Palliative Care” were developed under the direction of the FOPH. They define palliative care and formulate the fundamental values and principles, describe the target groups, the settings for treatment and support as well as the service providers of palliative care. A broad circle of stakeholders from the whole of Switzerland participated in the preparation.

2.2 Sub-project Services

- **Care structures for specialised palliative care** The FOPH, CMH and “palliative ch” collaborated to draw up the “Care structures for specialised palliative care”. The document offers an overview of the required services in primary palliative care and in the specialised palliative care for the cantonal health and social departments and the local, regional and cantonal service providers.
- **Definition of Quality Criteria** Under the auspices of the Association “palliative ch”, three lists of quality criteria were prepared for specialised palliative care clinics and units (List A), for in-patient and mobile out-patient palliative services (List B) and for in-patient treatment in institutions for long-term care.
- **Verification of the quality of palliative care services** Under the auspices of “palliative ch”, the Swiss Association for Quality in Palliative Care “qualitépalliative” was founded. It awards the label for Quality in Palliative Care.
- **Care Planning in the cantons** The cantons were supported in their care planning with an information event for the cantonal public health departments, and a survey on the state of palliative care services.

- **Indication criteria for specialised palliative care** A working group under the direction of the CMH prepared the "indication criteria for specialised palliative care". They serve as a guideline for decision making when specialists need to be consulted or when the patient needs to be transferred into a specialised palliative care unit.

2.3 Sub-project Financing

- **Report "Provisions of palliative care in primary care and in the specialised field of out-patient and in-patient long-term care and their financing"** The report, prepared by the CMH and the FOPH, describes in detail the situation in regard to financing and identifies the major problems.
- **Amending the Health Care Benefits Ordinance** The Federal Department of Home Affairs (FDHA) adapted Article 7 paragraph 2 letter a of the Health Care Benefits Ordinance KLV as of 1 January 2012. The paragraph is now entitled "Measures for clarifying, advising and coordination".
- **Tarification of palliative care provisions in palliative units and clinics** A working group under the auspices of "palliative.ch" has the remit to create a performance-related, tariff structure that is uniformly applicable throughout Switzerland.

2.4 Sub-project Awareness

- **National Information Platform Palliative Care** The "National Information Platform Palliative Care" www.palliative.ch came on line on 30 August 2010 for patients, interested parties and professionals.
- **Key Messages on Palliative Care** In the scope of the communication concept on palliative care, key messages were prepared. They serve as guidelines such that palliative care can be presented in a uniform manner. These key messages were assessed in a preliminary test for their comprehensibility and acceptance by the public.
- **Brochure "Terminally ill – what to do now?"** With the brochure "Terminally ill – what to do now?", prepared by the FOPH, CMH and palliative.ch, the cantons and regions now have a ready-for-use information sheet available.

2.5 Sub-project Education and Training

- **National Concept «Palliative Care: Education and Training»** The FOPH and the Federal Office for Professional Education and Technology OPET, together with representatives of the organisations concerned and significant stakeholders, prepared a national concept on education and training in palliative care.
- **Integrating the knowledge and skills needed in palliative care in the learning objectives catalogue of the university medical studies** It was agreed with the Swiss Medical Inter-Faculty Commission (SMIFC) to establish a broader inclusion of palliative care learning objectives in the Swiss catalogue of learning objectives (SCLO). The Undergraduate Education Palliative Care working group, composed *inter alia* of representatives of the medical faculties of Switzerland, determined in an analysis of the current situation the need for action in various medical faculties and developed corresponding recommendations and solutions.
- **Establishing palliative care as an integral part in postgraduate & further education** Discussions are ongoing with the Association for Palliative Care and the Swiss Institute for Postgraduate & Further Education in Medicine (SGCI) and various Associations in order to clarify how and to what extent palliative medicine should be firmly established in postgraduate training courses and the corresponding postgraduate programmes.
- **Forum "Education, Training and Working in Palliative Care"** The forum "Education, Training and Working in Palliative Care" was created for discussing the implementation of the national training concept in the various study programmes and at the various course levels.

- **Preliminary analysis of postgraduate training in long-term care institutions** Curaviva received the mandate to prepare a report (preliminary analysis) on the promotion of in-house training in palliative care for employees without a specific training and/or with training as an assistant in residential or nursing homes, institutions for the handicapped and for community care employees (without formal training) in the out-patient field. This involved the collaboration with important stakeholders.
- **Concept «Training and Support for Voluntary Work in Palliative Care»** Under a mandate from the FOPH, a «National Concept Training and Support for Voluntary Work in Palliative Care» was developed by Caritas Switzerland and the Swiss Red Cross SRC. This defined the roles of volunteers in palliative care and proposed measures for an improved involvement.

2.6 Sub-project Research

- **National Research Programme “End of Life” (NFP 67)** Parallel to the development of the National Strategy for Palliative Care, a proposal for a national research programme NFP was written under the auspices of the FOPH. The Federal Council commissioned the Swiss National Science Foundation SNF in early 2010 to carry out the NFP 67 “End of Life”.⁶
- **Chair and Programme for the Promotion of Palliative Care of the SAMS** At the request of the FOPH the Swiss Academy of Medical Science SAMS examined its possibilities for promoting research in palliative care. In autumn 2012 it decided to create a long-term “endowed chair for palliative medicine” at a faculty of medicine and to launch a promotional research programme in palliative care.
- **Research Platform Palliative Care** The “platform for research in palliative care and end of life” (lprpc) has already been in place for some time in French-speaking and Italian-speaking Switzerland. A similar platform will be created in German-speaking Switzerland under the auspices of the FOPH and palliative ch.
- **Statistical Data Situation in the field of Palliative Care** In order to obtain an overview of the current data situation the FSO has examined the existing national statistics in regard to variables important in regard to palliative care.

3 Need for Action and Measures 2013-2015

It was shown that important synergies and dependencies exist between the six sub-projects of the first strategy phase. In order to take the indispensable interconnection between the topics more into account and to pool resources, the sub-projects «care» and «financing» as well as «education and training» and «research» were combined. Up to now the topic «volunteer work» was only considered under the sub-project “training”. As this perspective is too narrow, the formal volunteer work will be considered as a independent sub-project in the continuing strategy.

The action plan for progressing the strategy in the years 2013 to 2015 is based on the work of the past three years, the results of the self-evaluation, the feedback and discussions with numerous involved stakeholders as well as from an analysis of the current literature. Furthermore, a «Strategy Forum Palliative Care» was held on 30 May 2012 attended by some 60 representatives of the cantons and various organisations. Suggestions and proposals were put forward in five groups and have been taken into account in the action plan shown below.

⁶ cf. www.nfp67.ch

3.1 Sub-project «Services and Financing»

Need for Action

In the first strategy phase the focus in the area "services and financing" was on specialised palliative care. In the second strategy phase, attention will be directed to primary palliative care. More than 80 per cent of palliative patients can be treated and cared for in the context of primary palliative care. About 20 per cent of palliative patients require specialised palliative care services.

Defining primary palliative care renders the services and provisions of palliative care more comprehensible and consequently also more visible. These are the main prerequisites for seriously ill and terminally ill persons to obtain access to palliative care in Switzerland. In order to promote the implementation of palliative care in the cantons and regions it makes sense to offer a platform for exchange and reciprocal links.

Objectives and planned measures

1. Sub-project «Services and Financing»	
Overall objective of the sub-project	
Sufficient offers of palliative care are available throughout Switzerland. Access to the provision of palliative care is ensured for seriously ill and dying persons, independently of diagnoses, age or socio-economic status.	
1. Subordinate objective:	
The offers and provisions of palliative care in primary care are defined and indication criteria are specified.	
1.1.1	Highlighting the offers and provisions of palliative care in primary care: Definition and indication criteria
1.1.2	Recording the costs for palliative care in the long-term clinical setting and in outpatient care and treatment
2. Subordinate objective:	
Specialised palliative care provisions in inpatient institutions (hospital) and in paediatrics are available when needed.	
1.2.1	Development of a performance-related, uniform tariff structure throughout Switzerland for specialised palliative care in hospitals with palliative care missions (palliative care clinics/institutions)
1.2.2	Survey of the need for palliative care in paediatrics
3. Subordinate objective:	
Regional, cantonal and intercantonal synergies relating to strategies and offers in the field of palliative care as well as financing models are promoted by information exchanges between the cantons and the provision of implementation variants and best practice models.	
1.3.1	Support of the cantons in the implementation of required palliative care structures by the preparation of an exchange and information platform.
1.3.2	Promotion of eHealth applications in palliative care (benefits study)

3.2 Sub-project «Education, Training and Research»

Need for Action

In the last two years the "National Strategy Palliative Care" has created solid bases for strengthening palliative care in the areas of training and research. The work already begun should therefore be continued. In this regard the basis forms a consensus among all relevant stakeholders on the training objectives in palliative care. Moreover, specific measures for the various training levels have to be implemented in the sub-project "Training".

The promotion of research and the improvement of the basic data must also continue to be pursued in the coming years. Statistical data on the end of life should be increasingly analysed. The data form an important foundation for health care planning in the cantons and regions. Closing the existing gaps in training, teaching and research in palliative care will improve the quality of health care at the end of life for everyone.

Objectives and planned measures

2. Sub-project «Education, Training and Research»	
Overall objective of the sub-project	
Specialists and teachers who are active in palliative care are provided with the required appropriate level of expertise. Teaching and research in palliative care in Switzerland are significantly consolidated and contribute to the quality of health care at the end of life.	
1. Subordinate objective:	
The joint education concept "Palliative Care and Training" forms the basis for a coordinated implementation.	
2.1.1	Annual forum "Training and Working in the world of Palliative Care"
2. Subordinate objective:	
Palliative care is an integral component of the training, further education and continuous education of the university and the non-university health and social professions as well as for other relevant occupational groups.	
2.2.1	Incorporating palliative medicine in medical training
2.2.2	Incorporating palliative medicine in medical postgraduate training
2.2.3	Incorporating palliative care in non-university health and social professions as well as for other relevant occupational groups
2.2.4	Clarification of further action relating to the promotion of in-house training of non-specialised employees
2.2.5	Incorporating palliative care in non-medical university courses
3. Subordinate objective:	
Measures for the promotion of research in palliative care are continued.	
2.3.1	Promoting networking and coordination in palliative care research
2.3.2	Providing basic data relating to palliative care

3.3 Sub-project «Awareness»

Need for Action

The build-up of palliative care offers will only be successful when people know what palliative care is. In spite of various publicity campaigns, still too little is known about palliative care and its offers, principally in German-speaking Switzerland. It must be said that three years are a very short timeframe in order to make the population aware of a topic that was previously almost unknown. An aggravating factor is that dying and death are also still taboo subjects in Switzerland.

Surveys show that in society today, primarily suicide help organisations are perceived as a possibility for ensuring self-determination at the end of life. Other possibilities that can likewise contribute to strengthen self-determination at the end of life – such as palliative care, end of life arrangements, recognising and treating depression – are not well known in the population.⁷ However, knowledge of these offers is a prerequisite in order to be able to come to a decision on self-determination. Consequently, increased efforts are required in this area. Action is needed principally along the two axes "informing the population" and "informing health professionals".

Objectives and planned measures

3. Sub-project «Awareness»	
Overall objective of the sub-project	
The population and the health professionals in Switzerland know about the benefits of palliative care and are aware of their availability.	
1. Subordinate objective:	
Health professionals are made aware of palliative care through suitable channels.	
3.1.1	Target-group-specific flyers for health professionals
2. Subordinate objective:	
The information on palliative care for the population is developed for specific target groups.	
3.2.1	Informational flyers on palliative care for the population
3.2.2	Updating the brochure "Terminally ill – what to do now"
3.2.3	Identifying the needs of migrants at the end of life
3. Subordinate objective:	
The population is made aware of palliative care over suitable channels.	
3.3.1	Constructing a regional communication network
3.3.2	Informing the population

⁷ Federal Council (2011): Palliative Care, Suicide prevention and organised suicide assistance. Report of the Federal Council, p. 35

3.4 Sub-project «Volunteering»

Need for Action

Volunteer work in palliative care in Switzerland is a formal, institutionalised volunteer service that is organised as an independent group or integrated into an inpatient institution or attached to such an institution. Volunteer work in Switzerland today is financed by private and public organisations. Together with the salaried professional staff, volunteers play an important role in palliative care. However, there is a need for action in the areas of health care planning and organisational structures as well as in information on the formal volunteer work in palliative care. This is shown by a needs-assessment commissioned by the FOPH as well as by additional studies.

Objectives and planned measures

4. Sub-project «Volunteering»	
Overall objective of the sub-project	
The offers and services of the formal volunteer work in palliative care are known throughout the country and are used proactively by cantonal and communal authorities and health and social service organisations as well as by professionals for the care and support of seriously ill and dying patients and their attachment figures.	
1. Subordinate objective:	
Information is drawn up on the requirements relating to the management and coordination in the formal volunteer work in palliative care.	
4.1.1	Guidelines for the promotion of formal volunteer work in palliative care
2. Subordinate objective:	
Existing channels are used to promote formal volunteer work in palliative care.	
4.2.1	Existing information platforms are used to promote formal volunteer work
3. Subordinate objective:	
Information on services and offers of formal volunteer work in palliative care are communicated to the population.	
4.3.1	Dissemination of information for volunteers and the population

3.5 Interdisciplinary project

The interdisciplinary strategy pursues the objective of ensuring that after 2015 the promotion of Palliative Care is sustained in the long-term over and above the support in the context of the "National Strategy Palliative Care" of the FOPH and CMH.

Action Plan

5. Measures for project management	
5.1	Ensuring the long-term sustainability of Palliative Care after 2015
5.2	Supporting a National Palliative Care Day
5.3	Evaluating the National Strategy Palliative Care 2010-2015
5.4	Organising a final meeting in 2015

Further information and all documents are available in pdf form here:

www.bag.admin.ch/palliativecare

www.gdk-cds.ch

www.palliative.ch

The following brochures can be ordered free of charge from the BBL, Bundespublikationen (www.bundespublikationen.admin.ch):

- **National Strategy for Palliative Care 2013-2015** (Order No. 316.720, from November 2012)
- **National Guidelines for Palliative Care** (Order No. 316.716)
- **Indikationskriterien für spezialisierte Palliative Care** (Order No. 316.717)
- **Nationales Bildungskonzept «Palliative Care und Bildung»** (Order No. 316.718)
- **Versorgungsstrukturen für spezialisierte Palliative Care** (Order No. 316.719)

Appendix D

Palliative Care in Switzerland - a clinical perspective

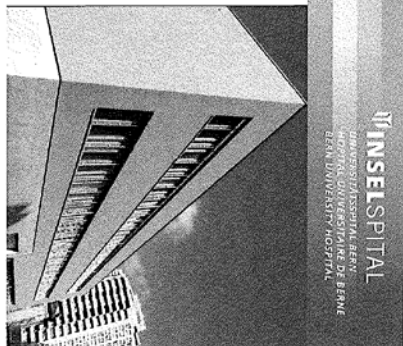
Steffen Eychmüller, MD, MMIE

Vice President palliative.ch

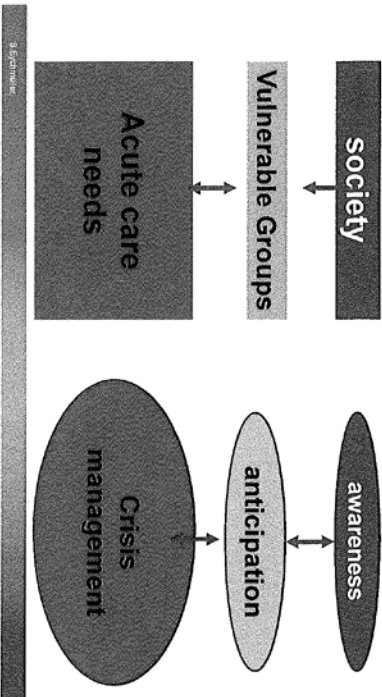
Center for Palliative Care
University Hospital Berne
Switzerland

steffen.eychmuller@insel.ch

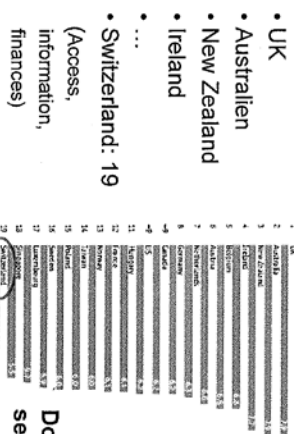
13th EAPC Congress
Prag 2013



CH: best in acute care



Switzerland – an unusual ranking



Potential barriers for anticipation in CH

- Expectation: «everything is feasible»
- Use of high tech and biotechnical innovation to survive longer
- The power of pharmaceutical industry + media
- Tradition of «leading medical system» - and money

But also:

- Right to die (physician assisted suicide)
 - Innovative law on advance care planning/ directives
 - Highly used complementary medicine
- «symptoms» of uneasiness in regard of quality end of life care?

summary

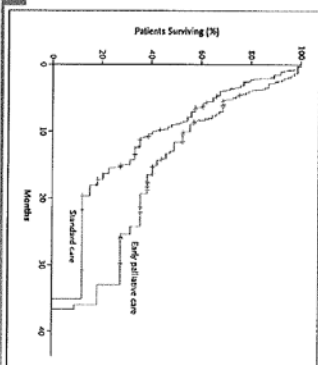
Compared with standard oncology care, integrated palliative care led to:

- Improved QOL
- Decreased psychological distress
- More accurate illness understanding
- Greater documentation of resuscitation preferences
- Less aggressive care at the end of life
- Longer survival (requires replication)

Early end of life preparation: best medication?

There is evidence

Early Palliative Care for Patients with Advanced NSCLC Lung Cancer



• Usual Care=8.9 months
• Palliative Care=11.6 months
• Entire Sample=9.8 months
• Log Rank p=0.02
Controlling for age, gender and baseline PS, adjusted HR=0.59 (0.40-0.88), p=0.01

Temel, Greer et al.,
NEJM. 2010

Anticipation saves money

Health Care Costs in the Last Week of Life

Associations With End-of-Life Conversations

Baohui Zhang, MS, Alice A. Wright, MD, Haidan A. Huskamp, PhD.

- 627 Patients with advanced cancer
 - End of life discussions in 31%
- costs: 35% less in the last 6 weeks of life

„The multimillion dollar- conversation“

Arch Intern Med. 2009;169(5):480-488

National strategy in Palliative Care

- The sociodemographic future
- The discussion on euthanasia / physician assisted suicide (2012: n = 356; nr of deaths: 63.000....)

Challenges within chapters

1. Organisation of care + finances (incentives??)
2. Education: more than cancer, interprofessional; basic AND specialist.....
3. Research: one academic chair... *no academic chair*
4. Public awareness/ professional recognition: profil of PC *weak*
5. Integration of volunteers: regulations/ professionalism


role was in care through all with care, it's not just being palliative

Palliative Care is going home: Learning from India and Australia

- End of life health literacy: loss and death education
- Community involvement: a strenght of Switzerland
- Normalisation of dying: adapting expectations
- It is (all) about money: developing chronic care pathways, strengthening primary palliative care

in some places have the concept no council are still come from the population

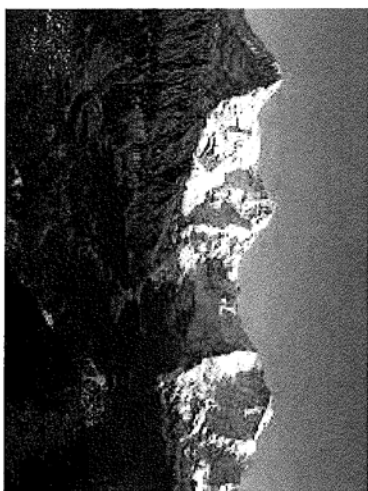
Organisation: PC as a change agent for chronic care and end of life preparation?



The meaning of life

People study for weeks for a birth
Why not study for a death?

<http://www.pilotlight.org.au/Dying-to-Know>



Thank you very much for your attention!

For further discussion: steffen.eychmuller@insel.ch

Appendix E



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End of Life Issues and Decision Making Forum

4 May 2013

Summary Report

Thank you for attending the recent forum. We are pleased to provide you with a short summary of the key outcomes of the End of Life Issues and Decision-Making Forum, held by the ACT Local Hospital Network Council (LHNC) on the 4th May 2013 at University House. The Forum was attended by over 90 consumers, clinicians, health and aged care sector staff and other interested citizens, and the evaluation feedback demonstrated a high level of satisfaction with the event. This summary focuses on the key themes of the World Café consultation session held in the afternoon, and the final recommendations.

The formal aims of the event were: to stimulate awareness around the importance of discussing and documenting decisions about future health care; to assist the ACT Local Hospital Network Council to better understand the impediments both within the community and among clinicians to discussing advance care planning processes and the provision of end-of-life palliative care services.

There were five presentations in the morning from: Dr Imogen Mitchell, Director, Intensive Care Unit, Canberra Hospital; Dr Peter Saul, Senior Specialist in Intensive Care and Head of Clinical Unit in Ethics and Health Law at University of Newcastle; Professor Jane Hall, Director of Strategy, Centre for Health Economics Research and Evaluation, University of Technology Sydney (pre-recorded); Ms Lorraine Walker, ACT Chief Magistrate; and Dr Adele Stevens, Vice President, Health Care Consumers Association.

Key themes from World Café consultation session

A full 19-page report has been provided to the LHNC for their consideration. It includes all comments recorded at the tables and plenary (a rich set of ideas and perspectives), and provides a thematic analysis of them and the recommendations. Some of the key themes are given below.

- We need to create a healthier and more open culture where talking about death and dying is open and normal. We should expect and plan for a good dying experience where possible.
- There needs to be a significant community-driven promotion program aimed at both education and culture change to increase awareness about what end-of-life means, when it might start, and the implications of various care pathways. The program should promote the need to talk about death and dying and encourage people to have the conversation with their family and friends. It should inform people about the decision-making options including advance care plans. It should foster early discussions rather than leaving them until too late.
- Engaging with Culturally and Linguistically Diverse (CALD) communities will need a more diverse and sensitive approach to allow for differing cultural beliefs and practices.
- Hospital, aged and primary health care systems and services should prioritise action by their staff on advance care planning, respecting the plans, and develop policies and allocate responsibilities accordingly.
- Information and forms for undertaking advance care planning should be readily available.
- Better systems for recording plans in an accessible manner, e.g. on a national database or via advance care plans on e-health database, or on Medicare Cards (c.f. organ donation), and transferability and reciprocity of documentation across states.
- Better education programs are needed for clinicians and other staff within health and aged care sectors about end of life; about how to have conversations about death and dying; how to recognise one's own beliefs and



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biases, and how to respect consumers' wishes at life's end. Include clear information and guidance to clinicians to allay litigation fears (or to clearly spell out boundaries.)

- Clarification of medico/legal issues, including legislative reform if necessary, to protect health professionals who decide not to provide futile treatment/s and to give confidence to consumers that their individual wishes will be respected.
- Hospitals need better systems to both recognise people's advance care planning documents and choices, but also to recognise futile care more clearly and make referral to palliative care easier (ACT Health are currently developing a Care of the Dying Pathway). Palliative care services will need to be enhanced to facilitate this.
- People need to develop more trust in the system and the perceived link in the public's mind between euthanasia and ACP, economic health decisions, and the fear of the 'slippery slope' need addressing.

Recommendations

A set of recommendations were generally endorsed although presentation (screen size) and timing meant that there was not a detailed discussion about exact wording. Evaluation feedback confirmed these recommendations and reasonably reflected the discussions. These recommendations have been edited slightly to clarify meaning and intent.

1. **Increase community engagement and awareness about end of life care.** There needs to be significant engagement and education with the diverse communities in the ACT to increase understanding of what happens at the end of someone's life; to understand the range of perspectives on this issue and people's needs, and to normalise discussions of end-of-life. This will need to be addressed with sensitivity and in different ways with the various culturally and language diverse communities.
2. **Increase community awareness of advance care planning.** Linked to the above, there is a need to increase awareness of ACPs, e.g. media, social network and education campaigns targeted at various age cohorts to make information and specific purpose forms made widely available (e.g. in CanberraConnect outlets now).
3. **Legitimate and resource ACP, including training staff.** Primary health care professionals (e.g. community health and practice nurses, nurse practitioners, aged care staff should be funded and authorised to undertake ACP with their clients to ensure people have the opportunity to have these conversations especially with their families well before they access the acute care setting. This will require better training of staff at several levels and sectors about end of life options and recognition of ACP. Health professionals should be trained in how to have those direct conversations about death and dying with consumers and their families, and how to recognise the required key decision points needed.
4. **Clarify the law.** Clarify (review and revise if necessary) the legal framework for ACP and create simpler legally binding tools to enable ACP. This would involve health professionals, ambulance and aged care staff, consumers and the legal profession. Move towards a common framework and common documents if possible.
5. **Ensure ACPs are easily available and systems act upon them.** More emphasis is required on appropriate systems within health services to recognise/seek ACP or other documentation so that consumers' knowledge and choices are respected. Consider how ACPs could be portable with consumers.
6. **Recognising futile care.** Regardless of consumers having an ACP, the LHNC should ensure systems within hospitals and RACFs enable futile care to be legitimately recognised and which more easily enable clinicians to desist from or withdraw care and redirect patients to palliative / end of life care.

Feedback on this report can be sent to LHNCouncil@act.gov.au.

Appendix F

LAW ON EUTHANASIA

Article 1

The present law regulates a matter pertaining to article 78 of the Constitution.

CHAPTER I General provisions

Article 2

In the application of the present law, **euthanasia** is defined as **the act, performed by a third person, which intentionally ends the life of a person at the request of that person.**

CHAPTER II Pre-conditions and procedure

Article 3

§1. **The physician who performs euthanasia is not performing an unlawful act** if s/he has ascertained that:

- The **patient** is an adult or an emancipated minor, **capable and conscious at the time of his/her request;**
- the request is made **voluntarily, is well-thought-out and reiterated**, and is not the result of outside pressure ;
- the patient is in a hopeless medical condition and complains of constant **and unbearable physical or mental pain** which cannot be relieved and is the result of a **serious and incurable accidental or pathological condition;**

and s/he has complied with the conditions and procedures prescribed by the present law.

§2. Irrespective of complementary pre-conditions that the physician might wish to add to his/her intervention, s/he must, firstly and in all cases:

- 1° **inform the patient** of the state of his/her health and of his/her life expectancy, discuss with the patient his/her request for euthanasia and the therapeutic measures which can still be considered as well as the availability and consequences of palliative care. The physician must have reached, with the patient, the conviction that there is no other reasonable solution to the situation and that the patient's request is entirely voluntary;
- 2° ascertain the persistent nature of the patient's physical or mental pain and of his/her reiterated wish. To this end, the physician will conduct **several interviews** with the patient, reasonably spaced with due regard to the evolution of the patient's condition;
- 3° **hold a consultation with another physician regarding the serious and incurable nature of the condition**, specifying the reason for the consultation. The consulting physician will study the medical record, **examine the patient** and ascertain the constant, unbearable and unrelievable nature of the physical or mental suffering. He/she will then write a report of his/her findings.

The consulting physician must be independent, from the patient as well as from the treating physician, and be competent concerning the pathological condition of the patient. The treating physician will inform the patient of the results of this consultation;

- 4° if a treatment team is involved, discuss the patient's request with the team or with some of its members;
- 5° if this is the wish of the patient, discuss the patient's request with those persons close to him/her that s/he designates;
- 6° ascertain that the **patient has had the opportunity to discuss his/her request with those persons.**

§3. Should the physician be of the opinion that death is not to be expected **within a short period of time**, h/she must, in addition:

- 1° **obtain a consultation with a second physician, either a psychiatrist or a specialist of the patient's pathology**, specifying the reasons for the consultation. The consulting physician must study the medical record, examine the patient, ascertain the constant, unbearable and unrelievable nature of the physical or mental suffering and of the voluntary, well-thought-out and reiterated character of the request. He will write a report of his findings. The consulting physician must be independent, from the patient as well as from the treating physician. The treating physician will inform the patient of the results of this consultation.
- 2° **allow at least one month between the patient's written request and the euthanasia.**

§4°. The patient's **request** must be made **in writing**. The document is drawn up, dated and signed by the patient. If the patient's condition makes this unfeasible, his/her request will be taken in writing by an adult of the patient's choice. That person should not benefit financially from the death of the patient.

That person will specify that the patient is unable to express his/her request in writing and why. In such cases, the request will be written in the presence of the physician and the aforesaid person will name the physician in the document. This document must be included in the **medical record**.

The patient may cancel his/her request at any time, in which case the document is taken out of the medical record and returned to the patient.

§5°. All the requests formulated by the patient, as well as the steps taken by the treating physician and their outcomes, including the report(s) from the consulting physician(s), will be entered routinely into the medical record.

CHAPTER III

Concerning the living will

Article 4

§1°. In anticipation of the eventuality when s/he would no longer be able to express his/her wish, every capable adult or emancipated minor may leave a written declaration of his/her wish that a physician should perform a euthanasia should this physician recognize:

- that s/he is the victim of a serious and incurable accidental or pathological condition;
- that s/he is **unconscious** ;
- and that this constitutes an irreversible situation in the current state of scientific knowledge.

The declaration may designate **one or several trusted persons of age**, listed in order of preference, who will acquaint the treating physician with the wish of the patient. In case of refusal, impediment or death of the first designated person, the second person on the list takes over, and so on. Neither the treating physician, nor the consulting physician, nor the members of the treatment team, may be designated as trusted persons.

This declaration may be made at any time. It must be made in writing, in the presence of two adult witnesses - one of whom at least had no material interest in the death of the author of the declaration – dated and signed by the author, by the witnesses and, wherever applicable, by the designated trusted person(s).

If the person who wishes to make a living will is physically and permanently unable to write it and to sign it, his/her declaration may be taken down in writing by a selected adult who should not have any material interest in the death of the person making the declaration, and in the presence of two adult witnesses, one of whom at least has no material interest in the death of the person making the declaration. The declaration must then specify that the person making the declaration is unable to write and sign it, and for what reasons. The declaration must be dated and signed by the person who has put the declaration in writing, by the witnesses and, when applicable, by the designated trusted persons.

Attached to the declaration, a medical certificate will confirm the permanent physical incapacity.

The declaration will be invalidated unless it was made or confirmed **less than five years** before the onset of the person's incapacity to express his/her will.

The declaration may be withdrawn or modified at any time.

Through the services of the National Register, the King will determine the procedures relating to the presentation, safe-keeping, confirmation, withdrawal and communication of the declaration to the physicians concerned.

2°. The physician who performs euthanasia following a living will as defined in §1, is not performing an unlawful act if s/he has observed that the patient:

- is suffering from a serious and incurable accidental or pathological condition;
- is unconscious;

- and that this situation is irreversible according to the current state of medical knowledge;
- and that the physician has complied with the conditions and procedures prescribed by the present law.

Irrespective of complementary pre-conditions that the physician might wish to add to his/her intervention, s/he must, firstly and in all cases:

- 1°. consult with another physician regarding the irreversibility of the patient's medical condition, and informing him/her of the reasons for this consultation. The consulting physician will acquaint him/herself with the medical record and will examine the patient. S/he will write a report of his/her observations. If a trusted person is designated in the living will, the treating physician will inform that person of the results of that consultation.

The consulting physician must be independent from the patient as well as from the treating physician, and be well-versed in the pathological condition of the patient;

- 2°. if there is a treatment team that is in regular contact with the patient, discuss the content of the living will with the team or with some members of the team;
- 3°. if the living will designated a trusted person, discuss with that person the content of the patient's living will;
- 4°. if the living will designates a trusted person, discuss the content of the living will with those persons that the trusted person designates as very close to the patient.

The living will, as well as all the steps taken by the treating physician and the results of these steps, inclusive of the consulting physician's report, will be routinely inserted in the patient's medical record.

CHAPTER IV Concerning the declaration

Article 5

The physician who performs euthanasia will, within four working days, submit for registration the document mentioned in article 7, duly completed, to the **Federal commission of control and evaluation** described in article 6 of the present law.

CHAPTER V The federal commission of control and evaluation

Article 6

§1. A **Federal commission of control and evaluation** is created, which will hereafter be referred to as « the commission. »

§2. The commission is composed of **sixteen members** who are selected because of their knowledge and experience in the matters relevant to the mandate of the commission. **Eight** of those members are physicians, of whom at least four are professors in a Belgian university. **Four** members are either **law professors** in a Belgian university, or attorneys.

Four members are selected from environments entrusted with the problems of patients suffering from an incurable disease.

Membership in the commission is incompatible with a seat in one of the houses of parliament and with membership in the federal government or in a governmental body of a community or of a region.

The members of the commission are appointed, for a term of four years, by a royal decree after deliberation in a Council of ministers; the appointments take into account linguistic parity, each linguistic group will be composed of at least three candidates of each sex, and will reflect a pluralist political representation. A member's mandate ends automatically when the member loses that quality for which s/he had been selected. Those candidates who were not appointed as effective members are appointed as substitute members, according to a list determining the order in which they will be called. The commission is presided by one French-speaking and one Dutch-speaking president. The presidents are elected by the members of the commission who belong to their respective linguistic group.

The commission may deliberate validly only if two thirds of its members are present.

§3. The commission sets up its own rules of procedure.

Article 7

The commission drafts a registering document that must be completed by the physician each time s/he performs euthanasia ;

This document is made up of **two sections**. The first section must be sealed by the physician. It contains the following data:

- 1° the name, first names and address of the patient;
- 2° the name, first names, number in the national health insurance registry, and address of the treating physician;
- 3° the name, first names, number in the national health insurance registry and address of the physician(s) who has (have) been consulted concerning the request for euthanasia;
- 4° the name, first names, address and function of all the persons who were consulted by the treating physician, as well as the dates of these consultations;
- 5° if there was a living will and it designated one or several persons of trust, the name, first names of the person(s) of trust who intervened.

This **first** section is **confidential**. It is transmitted to the commission by the physician. It may be read only upon a decision of the commission, and in no circumstance may it be used as a source for the evaluation mission of the commission.

The second section of the document is also confidential and contains the following data;

- 1° the patient's gender, and date and place of birth;
- 2° the date, hour and place of death;
- 3° the serious and incurable - accidental or pathological –condition which affected the patient;
- 4° the description of the constant and unbearable suffering;
- 5° the reasons why this suffering has been deemed unrelievable;

- 6° the facts which confirmed that the request was made voluntarily, was well thought through and was repeated without any external pressure;
- 7° whether one could be of the opinion that the death would ensue before long;
- 8° whether there is a living will;
- 9° a description of the procedure followed by the physician;
- 10° the qualifications of the physician(s) who were consulted by the treating physician, with the dates of these consultations;
- 11° the qualifications of the persons consulted by the physician, with the dates of these consultations;
- 12° how euthanasia was performed and by what means

Article 8

The commission studies the registered and duly completed document received from the physician. The commission **ascertains, from the contents of the second section of the registered document**, whether euthanasia was performed in conformity with the conditions and procedures listed in the present law. When **in doubt**, the commission may, by a majority vote, decide to waive **the anonymity** of the document. The commission then proceeds to acquaint itself with the first section of the registered document. The commission may request from the treating physician that s/he communicates all the contents of the medical record which pertain to the euthanasia.

The commission renders a decision within two months.

When, **by a two-third majority vote**, the commission is of the opinion that the conditions set down by the law **have not been fulfilled**, it **sends the record to the prosecutor** of the place of death of the patient.

Whenever the cancellation of the anonymity reveals facts or circumstances that may affect the independence or the impartiality of a member of the commission, this member will withdraw or may be removed from the examination of this particular case by the commission.

Article 9

Within two years of the implementation of the present law, and thereafter every two years, the commission produces, for the benefit of the legislative bodies:

- a) a statistical report based upon the informations gathered from the duly completed second part of the registered document sent by the physicians in compliance with article 8;
- b) a report containing a description and an evaluation of the implementation of the present law;
- c) if needed, recommendations that may lead to a legislative initiative and/or other measures concerning the implementation of the present law.

In order to carry out those tasks the commission may gather all the relevant information from the various authorities and institutions. The information gathered by the commission is confidential.

None of these documents may contain the identity of any person mentioned in the records handed over to the commission within the framework of the control set down in article 8.

The commission may decide to communicate, to university research teams who might present a motivated request for it, statistical and purely technical information, exclusive of any data of a personal character.

The commission may decide to hear experts.

Article 10

The King puts an administrative structure at the disposal of the commission for the implementation of its legal tasks. The numbers and the linguistic distribution of the administrative personnel are set by a royal decree after deliberation in a Council of ministers, upon proposal from the ministers in charge of Health and of Justice.

Article 11

The commission's operating expenses and personnel expenses, as well as the remuneration of its members, are drawn in equal parts from the budgets of the ministers in charge of Health and of Justice.

Article 12

Whoever is involved, in whatever manner, in the implementation of the present law, must respect the confidentiality of the data which are entrusted to him/her in the exercise of his/her mission and which are related to such exercise. Article 458 of the criminal code is applicable to that person.

Article 13

Within six months following the handing over of the commission's first report and, if need be, of the commission's recommendations, as set down in article 9, the legislative bodies schedule a debate on that topic. This six-month delay is suspended during a period when the legislative bodies have been dissolved and/or during a period without a government which has the support of the legislative bodies.

CHAPTER VI

Special measures

Article 14

The request and the living will as set down in articles 3 and 4 of the present law are not binding.

No physician is bound to perform euthanasia.

None is bound to participate in euthanasia.

If the physician who receives a request refuses to perform euthanasia, s/he must inform in due time the patient or the trusted person, and specify his/her reasons. In case his/her refusal is based on a medical consideration, this consideration must be entered into the patient's medical record.

The physician who refuses to act upon to a request for euthanasia must, at the wish of the patient or the trusted person, transfer the patient's medical record to the physician designated by the patient or by the trusted person.

Article 15

The person who died following a euthanasia performed within the conditions imposed by the present law, is deemed to have died a **natural death** as far as the execution of the contracts of which h/she was a party, in particular insurance contracts.

The provisions of article 909 of the Civil Code are applicable to the members of the treatment team mentioned in article 3.

Article 16

The present law comes into force no later than three months after its publication in the Belgian journal of parliamentary proceedings.

Appendix G

CODEx VITAE-27-11-2011

LEGALIZATION OF ADVANCED DIRECTIVES IN BELGIUM

Jacqueline Herremans
Lawyer
Member of the *Federal Evaluation and Control Commission on
the Law on Euthanasia*
Member of the *Belgian Advisory Committee on Bioethics*

Legal framework

- LAW ON EUTHANASIA
28-05-2002
- LAW ON PALLIATIVE CARE
14-06-2002
- LAW ON PATIENT'S RIGHTS
22-08-2002

Law on euthanasia

- Decriminalization
not legalization
- act practiced by a third party intentionally ending the
life of a person at the person's request
- Three principal conditions :
 1. voluntarily, carefully and repeatedly, and without outside
pressure request made, by an adult patient
 2. unbearable physical or mental suffering
 3. serious and incurable injury or pathological condition

euthanasia	Patient's rights
Trusted person(s)	proxy
Validity : 5 years	No limit
irreversible unconsciousness	No possibility to express him of herself
Two witnesses	No formalism but it has to be written and signed
Possibility to be registered by the municipality Data bank for doctors	No legal registration
No compulsory: conscience clause	Compulsory

Projects : tag Do not resuscitate order

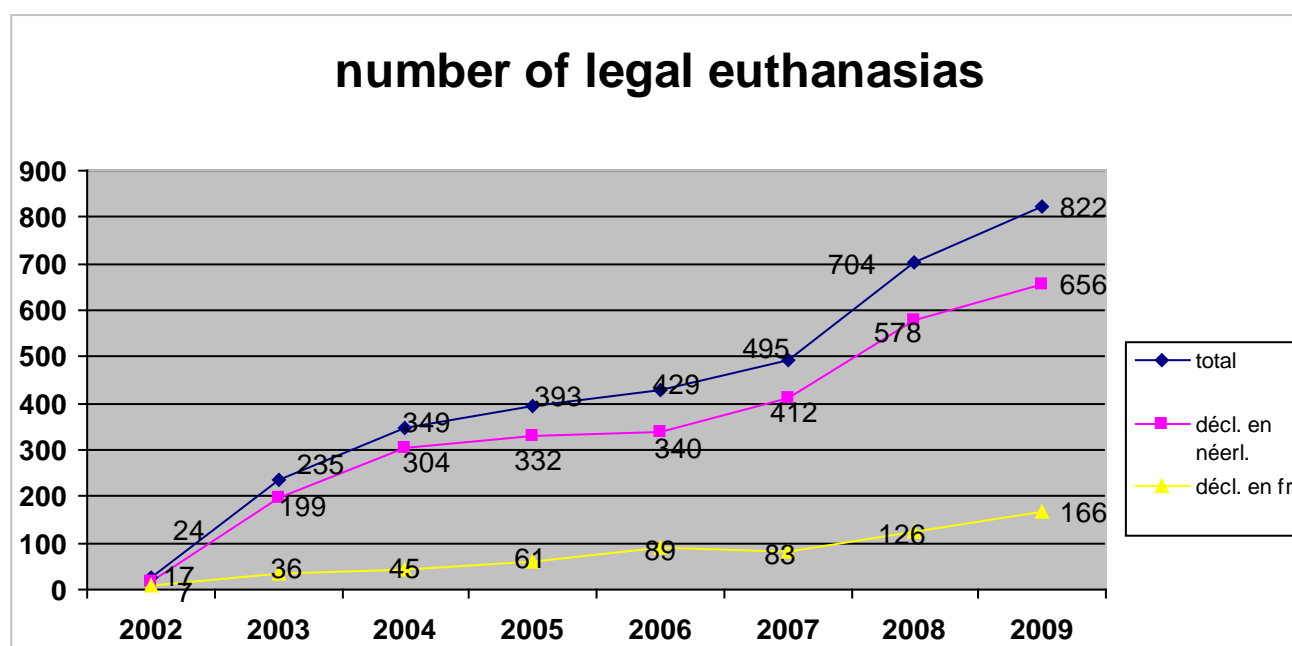


And european passport

Appendix H

FEDERAL COMMISSION FOR THE CONTROL AND EVALUATION OF EUTHANASIA (2002-2009)

The graph below illustrates the evolution of the practice of euthanasia since the law was implemented.



More than 3000 cases of legal euthanasia were recorded between September 22, 2002, when euthanasia was first decriminalized in Belgium, and December 31, 2009, when the last report was issued.

The first report, covering the period from September 22, 2002 to December 31, 2003, indicated that on average there were 17 cases of euthanasia per month. The latest report issued for 2008-2009 showed that there was an average of 64 cases of euthanasia per month for a total of 1526.

DESCRIPTION OF CASES EXAMINED

(Note: the % indicates those cases found in the 4th report for 2008-2009).

CASES OF CANCER AND NEUROLOGICAL DISORDERS

More than three-fourths (79%) of the persons seeking euthanasia suffered from generalized cancers or serious disabilities. For the most part these persons had gone through multiple treatments both curative and/or palliative. They were often followed by a palliative care team and there was evidence that the person's death was imminent in the days or weeks to come.

The neuromuscular ailments known to be lethal and in a lesser measure those caused by neurological accidents due to an illness or to an accident come in second place (7%). The other ailments have been rarely at the origin of an euthanasia. 8% of euthanasias concerned cases of ailments engendering great suffering where death was likely to occur after a long period of time. They have been practiced after the advice of two consultants has been sought and waiting one month after the written request was made, as the law requires.

AGE OF PERSONS CHOOSING EUTHANASIA

Close to three-quarters (73%) of the persons choosing euthanasia were between the ages of 40 and 79 years of age. Rarely has someone under 40 years of age requested euthanasia and it is less frequent after age 80.

EUTHANASIA IS MOST OFTEN CARRIED OUT IN THE PERSON'S RESIDENCE

52% of euthanasias have taken place in the home of the patient or in a place where the patient was living (most often by a physician who is a generalist) : 44% of the cases took place in the person's residence and 8% in a nursing home facility. 45% have taken place in a hospital and 3% in other residences.

SOME PHYSICAL AND PSYCHOLOGICAL SUFFERINGS

For most of the illnesses, several types of suffering, both physical and psychological, were present simultaneously. The sufferings were described as constant, unsupportable and without any relief. The physical sufferings most often mentioned included *suffocation, digestive obstructions with vomiting, and pain*. *The psychic sufferings most frequently indicated were loss of dignity, loss of autonomy and despair*.

The characterization of the suffering is in large part subjective and depends on the personality of the patients, their conceptions and their values. The commission notes that in certain cases, one must take into account the person's age to estimate if the sufferings have to be declared unbearable.

Some members of the commission have expressed some reservations on the characterization of unbearable sufferings in the sense of the law, for the psychic sufferings linked up to a foreseeable dramatic future, in the course of the illness (for example evolving towards a coma, suffocation, or a paralysis). This was not the opinion of the majority of the commission.

These have not been followed by the majority of the commission.

A DEATH CALM AND RAPID IN A PROFOUND SLEEP

In 98% of the cases, death has been obtained by an intravenous injection which induces a deep unconsciousness (in general by an injection of Pentothal) and (except when death is produced in some minutes from this injection, which is frequent) then a paralyzing neuromuscular medication is injected which provokes death by stopping the respiration. The commission notes that after reading what is available in the medical literature one such manner of acting is effectively the most adequate for fulfilling the conditions required for a correct euthanasia: serene and quick death without suffering nor secondary effects.

As one knows that the administration of large doses of morphine is frequent in the last moments of life for relieving suffering, the commission notes that this manner of acting, when it has been utilized, has then been considered by the doctor as a treatment for the patient's suffering and not as an euthanasia. In these cases the doctor has not made a declaration, even though it has accelerated somewhat the death of the person.

THE CASE OF MEDICALLY ASSISTED SUICIDE

In 1% of the euthanasias, the unconscious state has been obtained by the administration of a barbiturate in a potion which the sick person has swallowed himself. In certain cases this administration has been followed by an injection of a paralyzing neuromuscular medication. When it is the sick person himself who ingests the medication, it is considered to be an act which perhaps may be qualified as a 'medically-assisted suicide'. This manner of proceeding is authorized by the law *as long as the conditions and the legal procedures for which euthanasia is authorized have been respected and that the act takes place under the responsibility of the physician present and ready to intervene*; the law does not impose in effect, the technique to utilize for the practice of euthanasia.

MORE DECLARATIONS IN FLANDERS THAN IN THE FRENCH PART OF BELGIUM

80% of the declarations have been reported in Flanders and 20% in the French part of Belgium (see chart above). Why is there such a great difference? Are the doctors in the French speaking part of Belgium more reticent to respond favorably to a patient's request for euthanasia than their colleagues in Flanders? Is the Francophone population less inclined to request death by euthanasia? Or are there several additional factors? The commission continues to ask this question but has not reached any conclusion.

Many of the declarations mention that the death occurred rapidly and calmly, in a serene atmosphere in the presence of individuals very close to the patient remaining during the act, and that some thanks have been addressed to the doctor.

None of the declarations have raised doubts that the essential conditions of the law were respected. No file has been transmitted to the prosecutor.