Use of lawful voluntary assisted dying by minors: Worldwide evidence

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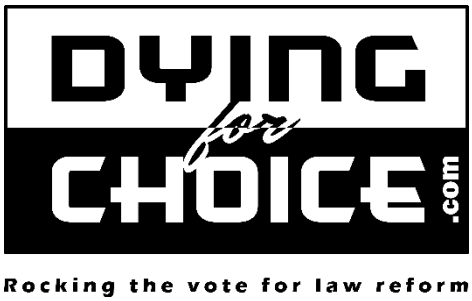

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Executive summary

Differences of opinion continue to be expressed regarding law reform to permit voluntary assisted dying (VAD) for minors: persons under the age of legal majority or adulthood, which in most jurisdictions is 18 years.

This study examines official evidence from lawful jurisdictions regarding the extent and nature of VAD amongst minors. Its aim is to facilitate calmer public discourse and more fully inform legislators considering VAD law reform proposals.

Findings

- VAD is currently a lawful choice for minors in the Netherlands, Belgium, Switzerland and Colombia.
- Dutch and Belgian legislation, and Colombian regulations, stipulate additional requirements regarding minors.
- Available Dutch and Belgian data reveal very low rates of use, between zero and three cases per annum, with parental involvement in decision making.
- There are no cases of VAD amongst minors on record in Switzerland.
- No official case data is available from Colombia. However, given the extremely low rate of VAD use overall, cases amongst minors are highly unlikely.
- While use of VAD laws by minors is rare, a review of case records reveals — as for adults — severe refractory underlying illness with extreme, unrelievable suffering.

Conclusions

Use of VAD by minors in lawful jurisdictions is rare, but nevertheless occurs with parental involvement in decision making, and otherwise as for adults: in cases of severe, refractory underlying illness with extreme, unrelievable suffering.

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Introduction

Voluntary assisted dying (VAD) law reform has been contentious, and reform to permit access by minors (persons under the age of legal majority, usually 18 years) even more so.

Debate has often been emotive, with almost no real experiential data to properly inform decision making by legislators considering VAD bills. Professionally researched articles about VAD amongst minors are scarce, for example one which compares Dutch and Belgian law expressly with respect to minors, but is confined to the legal requirements and doesn't cover the number or types of actual cases occuring under those laws.[1]

This anaylsis of official records attempts to fill this gap.

A number of jurisdictions around the world now provide access to VAD.

Use of VAD by minors is permitted in the Netherlands, Belgium, Switzerland and Colombia.

Amongst those that do, access is restricted to adults (18 years and older) in Luxembourg, Canada; all USA states with VAD statutes including Oregon, Washington, Vermont, California, DC, New Jersey, Maine, Colorado and Hawaii; and the Australian states of Victoria and Western Australia.

Access to VAD by minors is permitted in the Netherlands, Belgium, Switzerland and Colombia. This report examines the available official records of these countries in regard to use of VAD law by minors.

The Netherlands

The Netherlands' euthanasia Act of 2001 came into effect in 2002.[2] It codified in statute a set of regulations that had been in effect in preceding years, and despite claims otherwise, has not been altered at all since enactment in 2001.

The Act permits access to VAD by persons of age 12 and over. This harmonises the VAD rights of young patients with age 12 and 16 provisions in earlier Dutch patient rights legislation. It recognises that some minors are decisionally mature and competent to decide with parental approval (12–15yo), or with at least parental involvement but not necessarily approval (16–17yo).[3]

In *addition* to the due care criteria of the Dutch euthanasia Act for adults, the following provisions also apply in respect of minors:

- For persons 12–15 years, parent/guardian agreement is required.
- For persons 16–17 years, parent/guardian must be involved in the decision-making process, but the person ultimately decides.
- Persons 12–15 may not request VAD by advance directive, but those 16–17 years may, as adults may.

The number of VAD cases amongst minors is shown in Table 1. Use of the law by minors is rare, with a total of 14 cases between 2003 and 2019. This in part reflects the low rate of terminal illness and otherwise severe conditions at young ages compared with more advanced ages.

Dutch law permits VAD use by minors 12 years or older, with restrictions. Use is rare, with a total of just 14 cases since the Act came into effect in 2002.

Case examples

The Commission has published online notes regarding VAD cases for minors. The notes describe severe illnesses which were ultimately unresponsive to multiple treatment attempts, causing intolerable and unrelievable symptoms, for example:

Case notes 2004-01 describe a male in the 16–17 year old age group with major anaplastic astrocytoma, a cancer of the brain. He had been treated unsuccessfully with medication and radiotherapy. He suffered from epileptic seizures, ongoing hiccups, vomiting, double vision, shortness of breath, as well as medication-induced diabetes. Severe speech disorder, difficulty swallowing and incontinence also developed. He was confined to a wheelchair, and extensive palliation failed to help. He was judged decisionally competent. Decision making included his parents and grandmother, who respected and supported his request for VAD.

Case notes 2008-02 describe a female in the 16–17 year old age group with acute lymphoblastic leukaemia. She had undertaken chemotherapy and bone

Table 1: Number of Dutch VAD cases for minors by year.
Source: Euthanasia Commission annual reports; online case data

Year	Cases
2003	1
2004	1
2005	1
2006	0
2007	0
2008	2
2009	0
2010	0
2011	0
2012	0
2013	0
2014	1
2015	1
2016	1
2017	3
2018	3
2019	0

Case notes highlight severe illnesses, refractory to multiple treatment attempts, with extreme and unrelievable suffering.

marrow transplant, which were unsuccessful. In addition to breathlessness despite constant oxygen supplementation, and muscle and joint pain, she suffered from diabetes, hypertension and osteoporosis as a result of necessary heavy prednisolone use. She was completely bed-ridden and unable to find physical comfort, including severely decreased motor functionality which limited her ability to move herself, and requiring a diaper. Attempts to provide comfort with morphine and sleep medication proved counter-productive. Healing was not possible and she was expected to die within weeks. Judged decisionally competent, her parents were involved and respected her decision to use VAD.

C**ase notes 2015-59** describe a female in the 16–17 year old age group with acute myeloid leukaemia.[4] She had already endured an invasive stem cell transplant, which was unsuccessful. She suffered unbearably from nausea, fatigue and pain, as well as severe functional decline which robbed her of control over her life. She declined another stem cell transplant attempt as the treatment had severe side-effects but very small chance of success. With only weeks to live, she requested VAD. She was, with the involvement of her parents, judged decisionally competent, and was granted VAD.

Case notes 2016-58 describe a male in the 16–17 year old age group with advanced metastatic cancer. After many futile attempts at various therapies, brain metastases occurred, giving rise to intense and unrelievable pain. He

also experienced severe weight loss and fatigue, was bedridden and at risk of major seizures due to the brain metastases. He was judged decisionally competent to request VAD. His parents were involved in decision making and supported his choice.

Case notes 2018-48 describe a female in the 16-17 year old age group with a rare form of cancer present for seven years. Three years after first diagnosis a recurrence was found in the skull roof, with metastases in the neck vertebrae, ribs and pelvis. Seizures developed less than a year before death. Multiple treatments (surgery, radio- and chemotherapy) were unsuccessful and her condition deteriorated rapidly. Healing was no longer possible. She suffered from excruciating and intractable pain, and was completely bedridden. She was judged decisionally competent and her parents were involved in the decision.

While rare, severe and untreatable illnesses do occur amongst minors, which may lead them to consider VAD.

Case example 2018-51 describe a male in the 16–17 year old age group who was diagnosed with leiomyosarcoma a year and a half earlier. After two rounds of extensive treatments, lymph and lung metastases were detected and further healing was no longer possible. He suffered from extreme shortness of breath despite continuous oxygen supplementation, severe pain in the neck and shoulders, mucus formation and weakness. He was completely bedridden. He was judged decisionally competent and his parents supported his decision.

Despite the rareness of severe illnesses amongst young people that might lead them to consider VAD, cases clearly do occur, causing intense and unrelievable suffering as amongst adults.

The Groningen Protocol

The Dutch Groningen protocol is worthy of mention as it is wrongly maligned in macabre and false claims about child euthanasia in the Netherlands — supposedly around 650 cases a year.[5]

The protocol is a regulatory agreement (not legislation) between the Dutch prosecutorial authorities and paediatricians. It was developed in consultation with the Royal Dutch Medical Association (KNMG), ratified by the Dutch Paediatric Association (NVK) in 2005 and came into effect in 2006.

It consists of a portfolio of procedures regarding the peaceful termination of life of neonates with extreme and unrelievable suffering and no realistic chance of survival. In those rare cases, doctors who follow all the procedural requirements to reach a decision in consultation with the parents, and implement peaceful euthanasia, will not be prosecuted.

While there were 22 cases of euthanasia of neonates in untreatable extremis in the 9 years prior to the Groningen protocol, there have been only 3 cases in the 12 years since.

Main points about this protocol include:[5]

- It has nothing to do with the Dutch euthanasia Act because the Act requires a direct and express request of the person wishing to end his or her life. Children under the age of 1 clearly do not possess that capacity.
- Paediatric euthanasia has been found to occur in every country in which it has been studied, regardless of a Groningen-like protocol or VAD law for competent adults, including Italy, Spain, Sweden, Germany, the UK and France. The rate of neonatal euthanasia in France was found to be significantly higher than in the Netherlands.
- A formal Commission was established to review each reported case for adherence to the regulations and best medical practice.
- In the **9 years prior** to the regulation, a total of **22 cases** of neonatal euthanasia were reported to authorities, including for problematic reasons such as spina bifida.
- In **12 years since** the protocol came into effect, a total of only **3 cases** of neonatal euthanasia[*] have been reported, for extreme conditions such as Herlitz type epidermis bullosa, a fatal and untreatable illness with extreme internal and external blistering and bleeding.
- Thus, regulation has contributed to a decrease in incidence and increase in the quality of decision making. Cases are even more rare than prior to the protocol's implementation.

[*] In fact, only two cases are officially reported to the Commission, but for completeness I have included a third case which occurred in 2006 just before the Commission was constituted. This case was outlined to me by the KNMG in personal correspondence.

Belgium

Misinformation about Belgium's legal framework regarding VAD amongst minors is common, including misleading statements advanced by vested interests. For example, the European Institute of Bioethics, which campaigns against all forms of VAD, stated that:

> "*On 28 February 2014 … Belgium became the first and only country to authorise euthanasia of minors without specifying that any conditions with respect to their age should be met*." — Van De Walle 2017[6]

Surprisingly, even some statements made in scholarly, peer-reviewed journal articles are misleading:

> "*Belgium's regime did not originally extend to minors*." — MacIntosh 2016[1]

> "*In 2014, Belgium became the first country in the world to allow euthanasia of minors, irrespective of their age*." — Cohen-Almagor 2018[7]

Belgium's euthanasia Act was passed and came into effect in 2002.[8]

Belgium's 2002 assisted dying Act permitted certain ("emancipated") minors over the age of 15 to access VAD.

It permitted access to VAD by "emancipated" minors. In Belgium, emancipation is a special court determination regarding maturity and consequent decisional rights, pursuant to an application made by the minor or a parent/guardian under Belgium's consolidated civil code articles 476–487.[9] Such a determination is available only to those who have reached the age of 15. Thus, minors under the age of 15 could not lawfully access VAD.

Provided a minor could produce a court certificate of emancipation, the Act contained no additional requirements compared to adults, and offered all options available to adults, including request by advance directive.

In 2014, Belgium's parliament amended the euthanasia Act.[10] The amendments retained the "emancipated minors" provisions and added access, with new requirements, for non-emancipated minors:

- Capacity for discernment (decision-making capacity); and
- Condition/s causing suffering must be physical; psychological-only suffering excluded; and
- Death must be foreseeable in the short term; and
- Compulsory consultation with a child psychiatrist or psychologist to determine and attest in writing the minor's decision-making capacity; and
- Parents/guardian must agree with the minor's request, documented in writing; and
- A request may not be made by advance directive.

It is important to note that *age* provisions in VAD laws are *proxy* provisions for decisional capacity. The law in most jurisdictions *presumes* that an adult (i.e. having reached the legal age of majority) holds full decisional capacity. If substantive doubts occur, an appropriate mental health professional must determine and certify that the capacity does not exist at the appropriate level for the relevant context, before decisional rights can be lawfully curtailed.

The 2014 amendment additionally granted access to unemancipated minors with physical (not mental-only) illness, professionally tested and verified decisional capacity regarding VAD, as well as parental agreement.

The 2014 revisions to the Belgian Act, therefore, appropriately insert a *direct* (not proxy) measure and compulsory professional test of decisional capacity for unemancipated minors. To this is added the security of mandatory parental or guardian decisional assistance and agreement.

As in the Netherlands, use of VAD by minors in Belgium is rare, both before and after the 2014 amendments (Table 2): 8 cases in total from 2003 to 2019.

Three of the four cases since the 2014 revision of the Act were in respect of unemancipated minors; individuals who would not have qualified prior to the Act's 2014 revision.

The Commission reviewing each of these cases reports that child psychologists or psychiatrists formally confirmed decisional capacity, and that many other physicians and care providers were consulted in addition to

Table 2: Number of VAD cases in Belgium for minors by year.
Source: Federal Commission for Control and Evaluation of Euthanasia annual reports

Year	Cases
2003	1
2004	2
2005	0
2006	1
2007	0
2008	0
2009	0
2010	0
2011	0
2012	0
2013	0
2014	0
2015	0
2016	2
2017	1
2018	0
2019	1

Notes: Two of the three cases in 2016/17 (biennial reporting), and the 2019 case, were in respect of unemancipated minors.

the mandatory procedures.[11] All cases were reported in great detail and approved unanimously by the Commission.

Without distinguishing between emancipated and unemancipated minors, the Commission reports that the underlying illnesses in the three cases in 2016/2017 were:

- Severe Duchene muscular dystrophy;
- Glioblastomas: Cancer of the eye, brain and other parts of the central nervous system;
- Cystic fibrosis.

The Commission expressly noted its recognition of the intolerable suffering and untreatable nature of the illnesses of these minors. It complimented the legislature's amendment to the euthanasia Act to make it possible for unemancipated minors to consider and pursue VAD according to their own circumstances and values.

Like the Dutch experience, the Belgian experience shows that VAD cases amongst minors are rare, but that intolerable and unrelievable suffering can occur, and lead a minor to legitimately consider and pursue VAD.

In Belgium as in the Netherlands, VAD cases amongst minors are rare and occur in respect of severe illness causing intolerable and unrelievable suffering.

Switzerland

Switzerland does not oversee VAD by statute. Rather, article 115 of the Swiss penal code, in force since 1942, provides an exception to the crime of assisting a suicide: purely non-selfish motives.[12]

> *Any person who, for selfish motives, incites or assists another to commit or attempt to commit suicide is, if that other person thereafter commits or attempts to commit suicide, liable to a custodial sentence not exceeding five years or to a monetary penalty.* — Article 115

Assistance is therefore generally possible and is not mandated to occur through professional medical practice, although doctors are as a matter of practice involved to assess illnesses, prognosis, decisional capacity, seriousness of requests, and to prescribe the necessary VAD medication.

There is no formal code of regulation or standards of practice established by the government. Rather, a number of assisted dying associations have been established, notably Exit Deutsche Schwiez for German-speaking Swiss residents, Exit Suisse Romande for French-speakers — both founded in the early 1980s — and Dignitas for foreign nationals, established in 1998. There are other, smaller societies as well.

Each society maintains its own rules and procedures. The three societies mentioned above permit only adults to become members and use their services. Cases of assisted death are reported by each association to the authorities.

Official VAD figures reported by the Swiss Federal Statistical Office (FSO) for 2005–2014 indicate that no, or virtually no, persons under the age of 25 were assisted over this period.[13]

Recent correspondence with the FSO confirms there have been no cases of VAD amongst minors in its detailed data collected since 1998.

Despite no statutory or binding regulatory procedural requirements for VAD in Switzerland, the statistical office reports no cases of VAD amongst minors in detailed records kept since 1998.

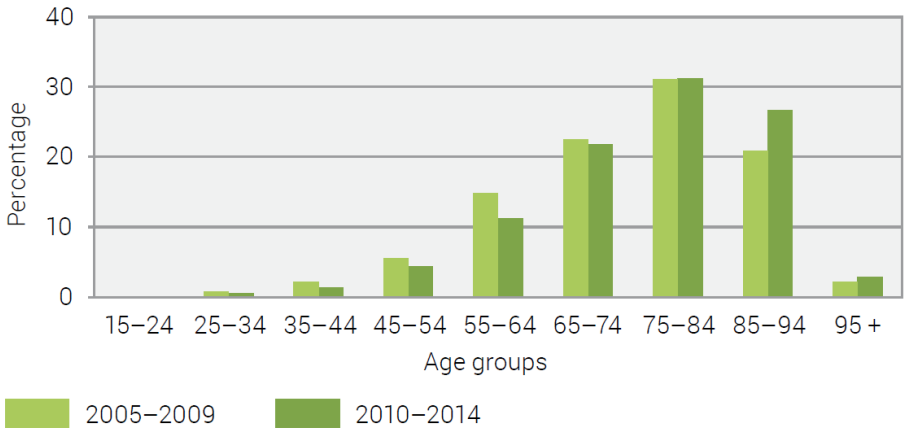

Figure 1: Assisted deaths in Switzerland by age
Source: Junker 2016, Figure G3

Colombia

VAD was considered illegal in Colombia until 1997 when the nation's constitutional court ruled assisted dying not a crime where a patient suffers from terminal illness, with no viable treatments, and has requested death.[14]

However, doctors were still reluctant to assist since conflicts in criminal law remained until 2015 when the Ministry of Health and Social Protection published a formal protocol for VAD.[15]

In 2018, the regulations were revised to permit access by children and adolescents from the age of 7. Additional safeguards include, similar to Belgium's provisions, compulsory testing for decisional capacity, and the approval of parents.[16]

No public official documents reporting the use of VAD in Colombia were found. However, an informal report suggests that between 2015 and 2018, around 40 people in total used the law.[17] This is a very low rate of incidence in a country with a population of nearly 50 million.

Given the low rate of adoption prior to 2018, it is likely there have been almost no, if any, cases of VAD use amongst minors.

Given the extremely low rate of VAD use in Colombia overall, it is likely there have been almost no, if any, cases amongst minors.

Conclusions

In the four jurisdictions where VAD is currently an option for minors, cases are rare in the Netherlands and Belgium, with up to three cases per year and many years with none: a total of 14 cases in the Netherlands and 8 in Belgium.

No cases have occurred amongst minors in Switzerland since at least 1998 despite a lack of official legislative or regulatory control, and cases are exceedingly rare or non-existent in Colombia.

Dutch and Belgian case details reveal that while illnesses that cause intolerable and unrelievable suffering amongst minors are uncommon, they do occur and meet the same types of criteria that prompt adults to consider and pursue VAD.

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