Assisted dying practice
in Benelux:
Whitepaper 1

Neil Francis

15th December 2016
Assisted dying practice in Benelux: Whitepaper 1

Neil Francis
15th December 2016

In this whitepaper, Benelux’ primary empirical data on assisted dying is analysed — including with new and advanced approaches — to provide fresh insights into contemporary practices. Investigation reveals that the assisted dying rate in Dutch-speaking cultures appears to be uniquely higher than in other cultures irrespective of the permissiveness of the legislative framework, yet is still practiced conservatively.

Table of contents

Introduction.................................................................3
Counts levelling off in the Netherlands & Belgium.....................4
Rates levelling off in the Netherlands & Belgium........................5
The Netherlands returning to former levels................................6
Cautious medical assessment in the Netherlands........................7
    Cautious medical assessment by new visiting teams................7
Cautious medical assessment in Belgium................................8
Cancer dominates underlying illnesses.................................9
Assistance in dementia/mental illness is rare..........................10
Even assisted cancer deaths are the exception........................11
‘Vulnerable’ hypothesis not supported................................12
Non-voluntary euthanasia: no ‘slippery slope’........................13
Preferred place of death not in acute care............................14
Belgium: Wallonia region rate much lower............................15
Other jurisdiction rates very much lower.............................16
Summary.........................................................................18
References........................................................................20

* Benelux is comprised of Belgium, the Netherlands and Luxembourg.
Introduction

Recently the Belgian Federal Commission for Control and Evaluation of Euthanasia released its biennial report card for 2014–15 assisted deaths, following a similar annual report for 2015 from the Netherlands. This whitepaper examines the empirical data from Benelux, along with data from the USA, to reveal important insights about how assisted dying laws function in lawful jurisdictions.

The Netherlands legislature passed its Termination of Life on Request and Assisted Suicide (Review Procedures) Act in 2001 and it came into effect in 2002, changing the country’s assisted dying framework from a regulatory one that had been in effect since the mid-1980s. Belgium passed its own Act in 2002 and which came into effect the same year, while Luxembourg followed suit in 2009. Unlike the Netherlands, neither Belgium nor Luxembourg permitted assisted dying prior to their Acts. While there are small differences, for our purposes the Acts of the three countries are much the same, and offer more liberal provisions that do statutes in various USA states, which restrict assisted dying to terminal illness and patient self-administration.

Each Benelux country has its own Euthanasia Commission — a statutory authority established specifically to collect, collate and publish reports of euthanasia activity under the law, and which provide official reports for scrutiny by the jurisdiction’s legislature. It is the data in these reports, along with primary empirical research data published in the peer-reviewed scientific literature, that are analysed in this whitepaper.

† For example, while the Belgian Act is silent about patient self-administration of the lethal medication, the Act is read as permitting it since the Act permits doctor administration.
‡ Strictly speaking, the Netherlands has five regional Euthanasia Committees: their work is collated through a single central register for reporting purposes.
Counts levelling off in the Netherlands & Belgium

Figure 1 shows the raw counts of assisted deaths in the Netherlands and Belgium, covering all full years from statute commencement to the most recent data. The rates are typical sigmoid (stretched-S-shaped) curves revealing a slow start, a faster middle, and a slowing of the rise in the most recent years. Much human behaviour adoption conforms to a sigmoid pattern.

However, it would be misleading to only report an increase in the assisted death counts without acknowledging at the same time an increase in the total death counts (Figure 2).

After an initial fall from 2003, since 2007 there has been a rise in the annual total number of deaths in both countries, consistent with an increasing and ageing population. The rise in total deaths from 2007 to 2015 was approximately 11% in the Netherlands and 8% in Belgium. It is relative to these changes that assisted dying is properly assessed.

Using a rate (assisted deaths as a proportion of total deaths) rather than raw figures also allows comparisons to be made between jurisdictions.
Rates levelling off in the Netherlands & Belgium

Figure 3 shows the rate of reported assisted deaths in the Netherlands and Belgium as a proportion of total deaths in each country. The rate has begun to level off in both countries, including a drop in the rate in both countries in 2015.

**Figure 3**: Reported assisted death rates in the Netherlands and Belgium as a percentage of all deaths
Source: Official euthanasia commission reports and government mortality data.

The Netherlands’ rate doesn’t commence from zero because practice transitioned from a regulatory framework to a statutory one. Belgium’s assisted dying statute was completely new, however.

Figure 4 illustrates the year-on-year change in assisted dying rates in the Netherlands and Belgium including second-order polynomial fits, showing that the increase is abating and both countries are approaching their own ‘settling’ levels.

**Figure 4**: Trends in assisted dying rate changes in the Netherlands and Belgium
Notes: Second-order polynomial trendline fit. Belgium 54.7% increase 2003-4 omitted due to high volatility of very small numbers in the first year of law.
The Netherlands returning to former levels

Periodic Remmelink research\(^6\) shows that in the Netherlands, assisted dying requests (or at least doctors ‘hearing’ requests) decreased substantially following the transition to a statutory framework, and have increased to former levels since then (Figure 5). Therefore, a significant part of the rise in the Dutch assisted dying rate since 2003 is a return to rates of assisted dying requests that occurred under the former regulatory framework, as both patients and healthcare workers got to grips with changes in the law.

Not only was the rate of requests suppressed after transition from a regulatory to a statutory framework, but the rate of doctors granting requests was also suppressed (Figure 6), further explaining the rise in the assisted dying rate since 2003.

\(^{\text{In the Netherlands, the transition from a regulatory to a statutory framework resulted in a temporary reduction in both patient requests for assisted dying, and their granting by doctors.}}\)

\(^6\) Remmelink research is conducted by university scholars and published in the peer-reviewed literature. The reports are informally named after Jan Remmelink who headed the Dutch government committee on euthanasia which released the first public study.
Cautious medical assessment in the Netherlands

Even in the 1990s prior to the change to a statutory framework, Dutch doctors refusing patient requests were discerning, believing the patient’s suffering was not unbearable and hopeless (35% of refusals),** there were still alternatives for treatment (32%), the patient was depressed or was having psychotic episodes (31%), the doctor did not personally support the case (20%) or that the request was not well-considered and enduring (19%).

At the time of statutory reform (2001–2), Dutch doctors refusing patient requests believed that the patient’s suffering was not unbearable and hopeless (52% of refusals), there were still alternatives for treatment (38%), had doubts about patient depression (29%), did not personally support the case (23%) or the request was not well-considered and enduring (18%).

Cautious medical assessment by new visiting teams

In 2012 the Dutch voluntary euthanasia society (NVVE) established new Levenseindekliniek (SLK) visiting teams to assess requests of patients whose usual doctors had declined their requests,† some of whom may have refused due to personal opposition to assisted dying or not supporting the patient’s case.

Whereas around half of requests at the time were granted by the patient’s usual doctor, significantly fewer — a quarter (25%) — of requests referred to the visiting teams in the first year were granted. Nearly half (47%) of cases not granted were refused by the visiting team (possibly because the legal due-care criteria had not been met), 19% died before their request could be assessed and 9% withdrew their request.

Like patients’ usual doctors, the visiting team doctors were reluctant to grant requests in less conventional circumstances: requests were granted for 33% of those with physical illness and for 5% with a psychological illness.†

Since refused patients usually maintain their desire for an assisted death and the new visiting teams grant a proportion of requests that previously remained refused, the overall rate of granting requests in the Netherlands will have increased since 2012. This would explain the further rise in the most recent assisted dying rates: around one third†† of the increase in the assisted dying rate from 2011 to 2012 is directly explained by the implementation of the new visiting teams.

** Doctors could report more than one reason for refusal.

†† The figure is approximate because data for the first twelve months of visiting team practice was not precisely aligned with the calendar year of Euthanasia Commission data.
Cautious medical assessment in Belgium

In Belgium — which was new to assisted dying law practice in 2003 — the rate of granting assisted dying requests rose from 55% in 2007 to 77% in 2013. In 2007 about 17% of requests were refused for reasons of personal objection and fear of legal consequences. By 2013, as doctors became more familiar with the law, these reasons had dropped to zero, accounting for much of the rise in the grant rate.

The most important reasons for granting requests in 2013 — apart from qualifying the legal criteria — were current suffering (87%), no prospect of improvement (78%), loss of dignity (52%), expected further suffering (48%), low expected quality of life (45%) and life not being prolonged needlessly (31%).

Amongst requests that were not granted in 2013, the most important reason for more than half (59%) was that they died before the assessment was completed, 20% failed to meet the legal criteria, the patient revoked the request (18%), the suffering was not judged to be unbearable (13%) and the request was not well-considered (10%). In 7.5% of cases, doctors refused the request because the patient was not terminally ill, even though terminal illness is not a requirement of the law.

Despite an increase in patient requests for assisted death rising from 3.8% in 2007 to 6.0% of all deaths in 2013, slightly more than half of assisted dying cases involved additional doctor and specialist palliative care consultations beyond the requirements of the law. Specialist palliative care services were involved in nearly three quarters of cases in 2013, with the research suggesting “a stricter assessment of legal eligibility criteria in 2013 than in 2007”.

The research indicates that doctors are neither hasty to grant requests nor inattentive in discerning qualifying cases from those that are not. Indeed, with indications that there is stricter assessment in more recent years, and still some refusals based on criteria that are not required in the legislation, doctors continue to demonstrate caution if not conservatism.

‡‡ In 1998 prior to the Euthanasia Act, some 2.1% of all deaths involved a serious request for assisted dying.
Cancer dominates underlying illnesses

By far the most common illness underlying a request for assisted dying is cancer. In 2015, nearly three quarters (72.5%) of Dutch assisted dying cases, and more than two thirds (67.8%) of Belgian cases, involved cancer (Figure 8).

Figure 8: Illnesses underlying assisted dying cases in 2015, Netherlands (left) and Belgium
Legend: Neuro=neurological/neuromuscular, Cardio=circulatory, Pulmo=airways, Dement=dementia, Mental=mental illnesses, Multi=multiple pathologies, Other=all other illnesses. Note: Belgium does not report dementia figures separately — included in Mental.

In terms of trends since statutory reform came into effect in 2002, cancer alone accounts for around two thirds of the total increase in cases in both the Netherlands (Figure 9) and Belgium (Figure 10). Trailing behind at very much smaller contributions to the increase are degenerative neurological (“neuro”) diseases and heart and lung diseases, with mental illness trailing all or most others.

In both the Netherlands and Belgium, cancer is overwhelmingly the underlying illness prompting patients to request assisted dying.

Mental illnesses are rare as underlying conditions.

Figure 9: Netherlands — underlying illness contribution to the rise in cases from 2004 to 2015
Source: Official euthanasia commission reports. Note: No disease data was published for 2003.

Figure 10: Belgium — underlying illness contribution to the rise in cases from 2003 to 2015
Source: Official euthanasia commission reports.
**Assistance in dementia/mental illness is rare**

There has been controversy surrounding assisted dying in the context of dementia and mental illness. As for any illness, the individual must meet all the statutory requirements and so must make considered requests for assisted dying while their decisional capacity is intact. The Dutch euthanasia commission reviews assisted dying cases of dementia and mental illness with additional scrutiny and care.\(^\text{16}\)

Assisted death in such cases is still very rare at less than 1% of all Dutch dementia deaths and less than 0.5% of all mental illness deaths, with a combined total of less than 1.5% of all dementia/mental illness deaths. This is remarkably similar to the total mental illness assisted death rate in Belgium at less than 1.5% (Figure 11).

This places in perspective those claims that criticize the increase in total assisted dying numbers while mostly or exclusively highlighting dementia and mental illness cases: implying or suggesting that dementia and mental illness are major contributors to the rise in assisted dying rates when they are not — cancer is.

In both the Netherlands and Belgium, less than 1.5% of all mental illness deaths were assisted.

---

**Figure 11:** Percent of dementia and mental illness deaths that were assisted

Sources: Official euthanasia commission reports, government mortality statistics by illness.

Note: Belgian ‘mental’ total mortality data not yet published for 2014/15, totals calculated by linear extrapolation of 2003-2013 data.

The number of assisted deaths related to dementia and mental illness can be expected to rise further: in the Netherlands, deaths from dementia nearly doubled from 5.0% of all deaths in 2003 to 9.4% in 2015, and deaths related to mental illness rose from 4.6% of all deaths in 2003 to 7.7% in 2015. In Belgium, deaths related to any mental illness rose from 3.0% of all deaths in 2003 to 4.5% in 2013. The granting of requests has risen in recent years, albeit at a very low rate.
Even assisted cancer deaths are the exception

Even amongst those dying of cancer in the Netherlands — which is now that nation’s leading cause of death (31%) as well as the most common reason for pursuing assisted death — fewer than one in ten cancer deaths was assisted (Figure 12). In Belgium the rate is less than one in twenty cancer deaths.

Figure 12: Percent of cancer deaths that were assisted
Sources: Official euthanasia commission reports, government mortality data by illness. Notes: Belgium rate is strictly percent of tumour deaths, though most tumour deaths are cancers. Belgium 2014-15 total tumour death data not available, calculated by linear extrapolation of 2003-13 data.

A further factor informing the increase in Netherlands cancer deaths (assisted and not) is the rise in cancer diagnosis (Figure 13). Since at least the late 1990s the rate of cancer diagnosis per head of population steadily increased, finally levelling off in 2011. With a five-year survival rate of around 55% (Dutch health data), the total and assisted cancer death figures would be expected to trail this trend by several years. This may further explain the rise in Netherlands assisted dying figures until 2014 before the drop in 2015.

Figure 13: Rate of cancer diagnosis in the Netherlands
Sources: Official government health and population data.
‘Vulnerable’ hypothesis not supported

There has been speculation in the past that certain groups would be ‘vulnerable’ to seeking assisted dying, including females and the elderly, who would therefore be overrepresented in assisted dying cases.

By gender, assisted deaths occurred in a majority of males in both the Netherlands and Belgium (Figure 14).

![Figure 14: Gender of assisted dying cases in the Netherlands and Belgium](image)


For age, little useful raw data is available, but matching data for assisted dying age cohorts for cancer death rates in Belgium was found for the years 2012–13 (Figure 15). (A majority of assisted deaths are in respect of cancer.)

![Figure 15: Belgian assisted deaths & total cancer deaths by age cohort (2012–13)](image)

Sources: Official euthanasia commission reports, government mortality data by illness.

The assisted dying age cohort profile is similar to the total cancer deaths profile, though skewed slightly towards younger ages. Amongst the elderly the odds of assisted dying is depressed rather than elevated. Given that illnesses prompting assisted dying choice predominate at older ages, the younger-age skew is possibly the result of lower rates of religion and higher acceptance of assisted dying amongst the younger.

The data is at odds with ‘vulnerable’ hypotheses: females and the elderly appear to be underrepresented, not overrepresented, in assisted dying cases.

---

88 The Belgian euthanasia commission only commenced reporting age cohorts in 10-year intervals in its 2012–13 report; and 2012–13 are the most recent two years for which government data for cancer deaths is available. The Netherlands euthanasia commission does not report age cohort data.
Non-voluntary euthanasia: no ‘slippery slope’

Non-voluntary euthanasia (NVE) is the practice of administering drugs to a person with an intention of hastening death, in the absence of a current request for it from the person. There may be therapeutic intentions, for example for relief of anxiety and diminution of consciousness to provide relief from suffering, but death is an expressly intended consequence. NVE is practiced in all countries in which it has been investigated, regardless of assisted dying laws and “the use of drugs with the intention to hasten death without an explicit request of the patient is part of medical end-of-life practice in the studied countries, regardless of their legal framework, and it occurs in similar fashion.”

Nevertheless, concerns have been expressed about the possibility of VE practice driving an increase in the practice of NVE. Contrary to such predictions, the rate of NVE has decreased with high statistical significance in both the Netherlands and Belgium since VE was permitted by statute (Figure 21). Indeed, the NVE rate in the Netherlands is now around the same level as in the UK: the UK providing the world’s gold standard for palliative care practice and which has never had an assisted dying law.

![Figure 21: NVE rates over time in the Netherlands, Belgium and UK](image)

Sources: Peer-reviewed primary research data (see discussion for references). Note: The 2001 Act came into effect in 2002.

In addition, if VE were a driver of NVE, then the Netherlands’ NVE rate would be higher than Belgium’s because its VE rate is higher: but the exact opposite is true. In addition, Switzerland’s NVE rate is lower than the Netherlands’ even though Switzerland has had an assisted suicide law for considerably longer: since 1942. The data indicates that NVE rates are driven by the general culture of a jurisdiction’s medical practice and are unrelated to any assisted dying law.

It is likely that both the deliberate increase in funding for palliative care introduced at the same time as legislation to permit assisted dying, plus the additional transparency and scrutiny of all types of end-of-life decisions after legalisation, have contributed to the reduction in NVE practice in the Netherlands and Belgium.
Preferred place of death not in acute care

In the Netherlands, the setting in which an assisted death occurred was mostly (80%) at home (Figure 16). There was a modest trend of assisted deaths out of acute (hospital) settings and into hospice and friends’ homes. This is in line with Dutch desires for place of death, with 88% preferring to die at home, 10% in hospice and 2% in acute care (hospital).20

Belgians have only a slightly lower preference (a few percentage points) to die at home, and a slightly higher preference to die in hospital, than the Dutch.21 Nevertheless, Belgian patients appear to have their place-of-death preferences met a little less often than those in the Netherlands.22

Belgium has also seen a decrease in acute care and increase in home-based assisted deaths from 2003 to 2007, as well as a further increase in assisted deaths in aged care (nursing) homes as hospital assisted deaths continued to drop from 2008 (Figure 17). This reflects general trends in Belgian deaths.23

The higher rate of hospital assisted deaths in Belgium may reflect hospital delivery of multidisciplinary palliative care: Belgian patients receiving such care are much less likely to die at home.24
Belgium: Wallonia region rate much lower

As a nation of two distinct regional cultures, Belgium provides a unique opportunity to assess possible cultural effects on assisted dying practice. Belgium is comprised of a ‘larger half’ living in the Dutch-speaking and more affluent north (Flanders/Flemish region), and a ‘smaller half’ in the French-speaking and less affluent south (Wallonia/Walloon region). Brussels is the third official region, accounting for a tenth of the population and with around two thirds of its residents speaking French.

Rates were calculated separately for the two major regions (see side box “Calculating separate region rates”).

The rate of assisted dying in Flanders is consistently much higher than it is in Wallonia (Figure 7) with an average odds ratio of 3.3 (p < 0.001). Judging the most recent three years (as the rates stabilise) the Flanders assisted dying rate is relatively close to (66%), while the Wallonia rate is only a small fraction (24%), of the Netherlands rate.

Thus, the higher rates in the Netherlands and Flanders may reflect Dutch cultural attitudes towards assisted death. The Dutch are strongly individualistic and straight-speaking with a wide tolerance of private behaviour and a more analytical cognitive style likely to reject emotional arguments. They prefer high social and personal order with strong internal structure and control. Each of these characteristics is likely to contribute to a higher acceptance and use of assisted dying.

Calculating separate region rates

The Belgian euthanasia commission reports don’t collate which regions its doctor filings originate from, but they do record the filing language (Dutch or French). Separate proxy assisted dying rates were calculated for the two major regions using filing language as a proxy measure for region along with separate mortality statistics for each of the three regions — and allocating two thirds of Brussels deaths to Wallonia (French language) and one third to Flanders. While the results should be interpreted with care because of the proxy measure, they are nonetheless quite informative.

Figure 7: Assisted dying rates in the Netherlands, Flanders and Wallonia

Sources: Official euthanasia commission reports, government regional mortality data. Note: Orange bars represent Dutch-speaking cultures.

Assisted dying rates in the Flanders north are around 3.3 times higher than in the Wallonia south of Belgium: much closer to the Netherlands rates.

*** Government and other published data.
Other jurisdiction rates very much lower

Luxembourg legalised assisted dying in 2009, with law very like the Netherlands and Belgium. The total number of assisted dying cases from 2009–2014††† was very small (N = 34), with 79% related to cancer and 18% related to degenerative neurological diseases.

In addition to Benelux, several USA states permit assisted dying though only in terminal illness and only by self-administration: Oregon since 1997 and Washington since 2008, and for which there is ample government data. Figure 18 compares the assisted dying rates amongst these jurisdictions.

The assisted dying rate in Luxembourg is even lower than that in its direct northern neighbour Walloon, the French-speaking southern region of Belgium. Luxembourg’s rate is around the same as Oregon and Washington whose frameworks are much more restrictive. While the Dutch-speaking assisted dying rates vary from 2.5% (Flanders) to 3.8% (Netherlands), rates in the non-Dutch-speaking jurisdictions are all less than 1.0%, with all except Wallonia below 0.5%.

This further suggests that Dutch-speaking culture may influence a relatively higher rate of assisted dying and that legalisation in other (non-Dutch) jurisdictions may result in lower rather than higher levels.

Nevertheless, assisted dying rates even in the Netherlands and Belgium are still low, even considering that the Netherlands has permitted assisted dying for three decades and so has a long history of practice and familiarity. Indeed, only the rates in the Netherlands and Flanders are readily ‘visible’ when visualised as a percent of all deaths in each jurisdiction (Figure 19).

†††Due to small assisted dying numbers, the Luxembourg euthanasia commission reports only biennially. Thus, the 2015 report will not be available until 2017.

Assisted dying rates in non-Dutch-speaking cultures are much lower, including in Luxembourg, whose assisted dying law is very similar to (mostly as liberal as) the Netherlands and Belgium.
Put another way, in Dutch-speaking jurisdictions in 2014, almost all deaths (>96%) were not assisted, and in non-Dutch-speaking jurisdictions virtually all deaths (>99%) were not assisted (Figure 20). Nevertheless, availability of assisted dying choice provided profound solace to many citizens, whether or not they ultimately pursued it.

As a proportion of all deaths, the assisted death rate in Dutch-speaking cultures is tiny; in non-Dutch-speaking cultures is it miniscule.
Summary
This new compilation and unique analysis of primary research data from statutory authorities and the peer-reviewed literature provides fresh insights into assisted dying practice in Benelux, including:

1. Rates of assisted dying in the Netherlands and Belgium have followed an expected sigmoid curve, now beginning to level out.

2. Several factors have contributed to the higher increase in the Netherlands rate, including recovery from a suppression of cases immediately following statutory reform, a rise in cancer diagnoses, and an increase in granting of assisted dying through new visiting teams launched in 2012.

3. Both Netherlands and Belgium doctors demonstrate caution if not conservatism when assessing assisted dying requests.

4. Despite most assisted dying occurring in cases of cancer, fewer than one in ten cancer deaths in the Netherlands and one in twenty in Belgium is an assisted death.

5. Other conditions such as degenerative neurological, pulmonary and circulatory illnesses each account for a very small proportion of the increase in cases since legalisation in Benelux.

6. The assisted dying rate in dementia and other mental illness is very low despite controversy around—and a tiny rise in granting of—such cases.

7. The hypothesis that females or the elderly would be ‘vulnerable’ to assisted dying law is contradicted by the data.

8. The rate of non-voluntary euthanasia has decreased significantly in both the Netherlands and Belgium since assisted dying was permitted by statute.

9. Assisted dying rates in Dutch-speaking cultures are significantly higher than in non-Dutch cultures, seemingly unrelated to the permissiveness of the jurisdiction’s legal framework.
Benelux country reported assisted dying rates (as a percentage of all deaths) as at 2014. The three countries have similar assisted dying laws.
References


10 Jansen-van Der Weide, MC, Onwuteaka-Philipsen, BD & Van Der Wal, G 2005, 'Granted, undecided, withdrawn, and refused requests for euthanasia and physician-assisted suicide', Archives of Internal Medicine, 165(15), pp. 1698-1704.


This document may be freely distributed provided it is not altered in any way.

Copyright © 2016 Neil Francis
DyingForChoice.com

www.dyingforchoice.com

PO Box 303
Mont Albert
Victoria 3207
Australia