

Guest editorial

Children and euthanasia: Belgium's controversial new law

Jo Samanta, BA (Hons), LL.M, PGCE
Reader in Medical Law, De Montfort University, Leicester

Introduction

On February 13, 2014 Belgium amended its law to extend the right to request euthanasia to terminally ill children. Despite strong opposition from some medical professionals and religious groups the law was passed on a vote of 86 to 44 (with 12 abstentions). Out of the three European countries that permit voluntary euthanasia Belgium has become the first to remove all reference to an age restriction. In the Netherlands, by comparison, children must be over the age of 12 whereas similar laws in Luxembourg apply only to adults.

Background

Belgium was the second country in the world (after The Netherlands) to legalise voluntary euthanasia in certain circumstances and subject to statutory safeguards. Belgium's 'Act Concerning Euthanasia' (Euthanasia Act 2002) came into effect in September 2002 and permits doctors to perform euthanasia at the request of competent patients provided that they have not been influenced in their decision by others. For the purposes of the Act euthanasia is defined as 'intentionally terminating life by someone other than the person concerned, at the latter's request' (section 2). Adult patients must be in a 'medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident.' (Euthanasia Act 2002 section 3§1).

The law provides patients with a right to request medical termination of life. It does not grant a right to euthanasia: doctors have a right to conscientiously object on moral or religious grounds. In similar vein whilst most public hospitals of Belgium are secular organisations some religious healthcare bodies have publicly opted out of allowing euthanasia to be carried out on their premises (Commission on Assisted Dying 2012a).

For adults the law requires that requests for euthanasia are 'voluntary, well considered, and repeated, and not the result of any external pressure' (Euthanasia Act 2002, section 3§1). Doctors must explain to patients about their clinical prognosis, life expectancy and discuss alternative options such as palliative care (Euthanasia Act 2002, section 3§2 (1)). Both patient and doctor must agree that there are no alternatives to euthanasia and the doctor must be certain of the enduring nature of the request (Euthanasia Act 2002, section 3§2 (2)). The patient's wishes must be discussed with any relatives chosen by the patient and the doctor must be certain that the patient has had the opportunity to discuss the request with any person of his or her choosing (Euthanasia Act 2002, section 3§2(5)(6)). Evidence is required that this remains their settled wish. In order to reassure the public and concerned parties regarding the operation of the Law on Euthanasia the Federal Control and Assessment Commission was set up shortly after the Act was

brought into force. The 16 member Commission, half of whom are doctors, carries out post hoc review of all reported cases to ascertain compliance with the legislation. Nevertheless, despite the existence and remit of the Commission as well as Belgium's strong societal support for voluntary euthanasia, this enthusiasm has not swayed certain sectors of the medical profession or the professional associations, which maintain their official stance of neutrality (Commission on Assisted Dying 2012b).

Extending choice to children

Although the age of eligibility for assisted dying in most permissive societies (that provide for assisted suicide as well as euthanasia) tends to be restricted to adults, prior to its recent amendment Belgium's Law on Euthanasia also extended to adolescents over the age of 15 who had been 'legally emancipated' by judicial decree (Lewis and Black 2012). To some extent, therefore, Belgium's law already provided for some, older, terminally ill children. Nevertheless, during the last 12 years the Commission Fédérale reports that only four cases of euthanasia have involved patients under the age of 20 years and none of these were children (Commission Fédérale De Contrôle et d'évaluation de l'euthanasie Cinquième Rapport aux Chambres Legislatives (Annees 2010 – 2011)). It is against evidence such as this that supporters of the reforms argue that the impact of the amendments to the law is likely to be very small.

In effect, the new law will permit children of any age to request euthanasia provided that they understand the consequences of their decision as verified and certified by a child psychiatrist or psychologist. The child must be in a 'medically futile condition of constant and unbearable physical suffering that cannot be alleviated and that will result in death in the short term' (Euthanasia Act 2002, section 3§1) and, although no age restriction is given, the child must also display the 'capacity of discernment' and be 'conscious at the moment of making the request.' (Euthanasia Act 2002, section 3§1). In addition, the child's decision must be supported by a parent or legal guardian who has a right of veto. These statutory safeguards are rightly stringent and will limit those children who qualify. On this basis it is anticipated that the potential impact of the change in the law will be limited, albeit that this is very necessary.

Typical arguments lodged against the reforms

Three main philosophical arguments are usually advanced by those opposed to voluntary euthanasia. The first is that euthanasia is wrong in principle and that the existing Law on Euthanasia should be revoked, rather than extended. The second concerns coercion, in that persons from vulnerable groups may be pressured into seeking death. Children, by their inherent status, could fall squarely within this category, a factor further complicated by the need to involve third parties

(those with parental responsibility and specialist doctors) in the decision-making process. The third is the 'slippery slope' argument which, in this context and at its most basic, asserts that laws which permit terminally ill autonomous adults to request euthanasia will lead inevitably to loosening of the law and permit other vulnerable groups being similarly allowed. In this way extending the law to children will be seen by some as being patent evidence of that 'slippery slope' in action.

And yet the new social and legal climate of many western jurisdictions emphasise personal autonomy and condemn all forms of discrimination. European law upholds the rights of competent children, as well as adults, as evidenced by international instruments such as the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR 1950, Article 8). More specifically, in the context of children, the United Nations Convention on the Rights of the Child asserts the central importance of upholding children's rights to self-determined choice (UNCRC 1989 Articles 12, 13 and 14 of the Convention).

Siegel et al, (2014), have argued persuasively that even competent children and adolescents will lack sufficient knowledge and that certain sense of self which adults often invoke as the rationale behind their requests for a medically assisted death. They assert that adults choose euthanasia for reasons other than pain, such as fear of losing control, not wanting to be a burden to others and preferring not to spend their final days being fully sedated. Children and adolescents, by comparison, are deemed to lack sufficient experiential capacity to nurture such sophisticated preferences against palliative care measures of last resort. Nevertheless, arguments such as these fail to explain how such characteristics of maturity can be acquired magically on the stroke of midnight on a child's eighteenth birthday and yet are absent two minutes before that crucial hour.

The fundamental difficulty here is that there is no fixed correlation between chronological age and decision making capacity. Age per se is a weak indicator of any child's capacity to understand, particularly when that criterion is used in isolation. Empirical evidence suggests that factors, such as living with chronic severe illness, will often influence cognitive development and maturity especially in the context of healthcare decisions (Fielding and Duff 1999). The 'experienced' child patient might therefore, very sadly, display a level of maturity and experiential cognisance that contradicts their chronological age. Competence or 'capacity for discernment' cannot always be assessed accurately by reference to age alone. For this reason the approach of the amended Law on Euthanasia, with its lack of reference to an age restriction, is surely the correct one.

Conclusion

The moral problem of euthanasia is a difficult one, and is all the more poignant where children are concerned. Laws that permit voluntary euthanasia for children are complex and intriguing philosophical problems that need to be grappled with not only in the abstract but also in reality. Belgium's amended legislation applies to the lives and deaths of real children. The point I make here does not concern the moral acceptability or otherwise of active voluntary euthanasia. Nevertheless, for a society which permits adults to request medically assisted death

to relieve their unbearable suffering, it would seem to be unfair and unjust not to extend that same compassion to competent children who are sufficiently mature for 'discernment'.

Whilst writing this piece I have been watching the antics of my two young sons wrestling and cavorting in the garden and it pains me to realise the implications of what I have written. I cannot even begin to imagine the devastating and heartrending circumstances that are likely to surround end of life decision making that is pertinent to this new Act. Nevertheless, for a society, like Belgium, which tolerates euthanasia in certain defined circumstances already, to deny children with capacity the same opportunities to end their suffering humanely, to the same extent as their older contemporaries, must surely be as unjust as it is discriminatory.

REFERENCES

1. The Commission on Assisted Dying (2012a) Report of the Commission chaired by Lord Charles Falconer: 144. London, DEMOS.
2. The Commission on Assisted Dying (2012b) Report of the Commission chaired by Lord Charles Falconer: 263. London, DEMOS.
3. Commission Fédérale De Contrôle et d'évaluation de l'euthanasie Cinquième Rapport aux Chambres Legislatives (Annees 2010 – 2011) Available at <http://www.ieb-eib.org/fr/pdf/rapport-euthanasie-2012.pdf>.
4. Euthanasia Act 2002 translated by Kidd D under the supervision of Nys H, Centre for Biomedical Ethics and Law, Catholic University of Leuven (Belgium); Kidd D, The Belgian Act on Euthanasia of May, 28th 2002, *Ethical Perspectives*.
5. European Convention on Human Rights (1950) Article 8 available at http://www.echr.coe.int/Documents/Convention_ENG.pdf
6. Fielding D and Duff A (1999) Compliance with treatment protocols: interventions for children with chronic illness *Arch Dis Child* **80**:196-200.
7. Lewis P and Black I (2012) The effectiveness of legal safeguards in jurisdictions that allow assisted dying' Commissioned Report.
8. Siegel A, Sisti D, Caplan A (2014) Pediatric Euthanasia in Belgium Disturbing Developments *JAMA* 311(19):1963-1964.
9. United Nations Convention on the Rights of the Child (1989) Articles 12, 13 and 14.

ADDRESS FOR CORRESPONDENCE

Jo Samanta, Reader in Medical Law, Leicester De Montfort Law School, The Gateway, De Montfort University Leicester, UK, LE1 9BH, email: JSamanta@dmu.ac.uk