

**Do children 'own' the right to die?****Professor Charlotte Phillips**

**If the right to die is an inviolable human right, does it necessarily – automatically, even – follow that children 'own' this right?**

**Introduction**

In June 2015, the Dutch Association of Paediatrics expressed itself in favour of a rather controversial change in the law. According to the Association, children who are terminally ill and suffer unbearably should be accorded the right to die. To date, Belgium is the only country in the world where a child, unhampered by age restrictions - in exceptional situations and under very strict conditions - can be allowed the option of active life-ending treatment. In this article the right to die will be discussed from a children's rights perspective.

**1. Right to life**

The right to life is a moral principle universally endorsed by humankind. It is the most important and fundamental human right incorporated in many a declaration, convention and covenant; to name but one: the Universal Declaration of Human Rights, which provides in article 3 that every human being has the right to life. According to the Human Rights Committee, derogation from this right is not permitted under any circumstances. Furthermore, the right to life should not be interpreted restrictively and requires States to take positive measures, for instance with regard to the reduction of child mortality, malnutrition and epidemics. In addition, States should refrain from acts of war and (mass) violence or other use of force which leads to the loss of human lives.<sup>1</sup>

<sup>1</sup> Human Rights Committee, General Comment no. 6 (1982), HRI/GEN/1/Rev.9 (Vol. I).

Although the Declaration of Human Rights applies to all humans - adults and children - it has long been recognised that children are particularly vulnerable and need special protection in certain circumstances; this conception has led to the development of a range of separate treaties specifically aimed at the rights of children.<sup>2</sup> The UN Convention on the Rights of the Child (CRC) - which has been ratified by all nations apart from the United States of America - provides in article 6 that every child has the inherent right to life and that State Parties are obliged to ensure, to the maximum extent possible, the survival and development of children. Other, regional, documents relating to children's rights, such as the African Charter on the Rights and Welfare of the Child, contain similar provisions. The right to life cannot be seen in isolation from other rights; to simply keep a child alive is not only insufficient, but also morally repugnant.

Children have the right to physical and intellectual development, adequate healthcare, education and to special protection. Children also have the right to express their own opinions about matters which affect them directly and their views should be given due weight in accordance with the age and maturity of the child in question.<sup>3</sup> Despite the fact that the responsibility for children ultimately lies with adults, we cannot and should not ignore the fact that children are - depending on their capability and skills - quite capable of forming their own ideas with regard to what is in their best interests. Which brings me to the following question: what if a child expresses a wish to die? With regard to children's right to life, the moral correctness or the validity of this right is indisputable; however, does this extend to the right to die?

**2. Right to die**

The paediatrician, children's advocate and author Janusz Korczak (1878 - 1942) was a great believer in child participation. He went as far as creating a Children's Republic in the orphanage he ran in the ghetto of Warsaw during World War II, consisting of a Children's Court, a Children's Parliament and a special orphanage newspaper.<sup>4</sup> Korczak formulated numerous children's rights, including the right of the child to die. This concept was born out of the idea that adults may be so focussed on the child staying alive - *coûte que coûte* - that their fear of losing that child effectively

<sup>2</sup> Cf. the Janusz Korczak's Declaration of Children's Rights, one of the first unofficial codifications of children's rights, the 1924 Geneva Declaration of the Rights of the Child, the 1959 UN Declaration of the Rights of the Child and the 1989 UN Convention on the Rights of the Child.

<sup>3</sup> Article 12 Convention on the Rights of the Child.

<sup>4</sup> G. Eichsteller, *Janusz Korczak - His Legacy and its Relevance for Children's Rights Today*, International Journal of Children's Rights 17 (2009), p. 382 - 383.

## INTERNATIONAL ASSOCIATION OF YOUTH AND FAMILY JUDGES AND MAGISTRATES

denies the child a worthy life. Although Korczak did not actively endorse childhood suicide, he was of the opinion that a child's right to a self-determined life may include death. It was his belief that when a child is deprived of the right to die, he is essentially deprived of the right to control his own life.<sup>5</sup>

In most countries, the right to die is not recognised in that suicide is considered to be unethical and euthanasia is illegal, as is assisting somebody to take his own life. There are many definitions of the term euthanasia in use . from mercy killing to the act of killing someone painlessly. but in legal terms it is best defined as: intentionally terminating life by someone other than the person concerned, at the expressed request of the latter.<sup>6</sup>

In April 2002, the Netherlands became the first country to legalise euthanasia,<sup>7</sup> followed by Belgium in that same year.<sup>8</sup>

The Dutch Termination of Life on Request and Assisted Suicide Act allows for the termination of life on request when the following due care criteria have been fulfilled:

- the patient's request is voluntary and carefully considered;
- the patient's suffering is unbearable and there is no prospect of improvement;
- the attending physician has fully informed the patient about his diagnosis and prognosis;
- physician and patient have come to the conclusion that there is no reasonable alternative in the light of the patient's situation;
- the physician has consulted at least one other, independent, doctor who has to have examined the patient and given a written opinion on the due care criteria referred to above;
- the termination of the patient's life or assistance with suicide is carried out with due medical care and attention by the attending physician.<sup>9</sup>

In the event that a patient is no longer able to express his own will, but has drawn up a written request for the termination of his life while still capable of determining his own best interests, the attending physician may comply with said request; the aforementioned due care criteria apply *mutatis*

*mutandis*.<sup>10</sup> The physician must report every instance of euthanasia or assisted suicide to a Review Committee for assessment. Should the Committee find that the due care criteria were not adhered to, the case will be handed over to the Public Prosecution Service for closer scrutiny.<sup>11</sup>

The 2002 Belgian Act on Euthanasia contains similar provisions, which are more explicit and elaborate. For instance, the patient's request for euthanasia is described as voluntary, well-considered and repeated, and not the result of any external pressure.<sup>12</sup> Also, when the physician is of the opinion that the patient is not likely to die in the near future, he has to . in addition to the consultation of a second, independent, physician . consult a psychiatrist or specialist in the disorder the patient is suffering from.<sup>13</sup>

Luxembourg became the third country to decriminalise euthanasia in 2009; the Law on euthanasia and assisted suicide is comparable to both the Dutch and Belgian system.<sup>14</sup>

In Switzerland, euthanasia is forbidden by law.<sup>15</sup> However, persuading or assisting somebody to commit suicide is permitted as long as the assistance or persuasion was not inspired by selfish motives, such as financial gain or other consequences that would benefit the actor.<sup>16</sup>

In France and Germany, euthanasia is illegal but there are special provisions in place which allow a physician to discontinue a patient's treatment under specific circumstances. In 2005, France adopted the Leonetti law,<sup>17</sup> which allows doctors to refrain from treatment that is useless, disproportionate or only aimed at artificially keeping patients alive,<sup>18</sup> and instead provide a terminally ill patient with palliative care which . as a side effect . may lead to his death.<sup>19</sup> In Germany doctors may cease treatment on similar grounds.

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<sup>10</sup> Article 2 subsection 2 Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding (Termination of Life on Request and Assisted Suicide Act).

<sup>11</sup> Articles 8 . 10 Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding (Termination of Life on Request and Assisted Suicide Act).

<sup>12</sup> Section 3 subsection 1 Wet betreffende de euthanasie (Belgian Act on Euthanasia 2002).

<sup>13</sup> Section 3 subsection 3 Wet betreffende de euthanasie (Belgian Act on Euthanasia 2002).

<sup>14</sup> Loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide.

<sup>15</sup> Article 114 Schweizerisches Strafgesetzbuch 1937 (Swiss Criminal Code).

<sup>16</sup> Article 115 Schweizerisches Strafgesetzbuch 1937 (Swiss Criminal Code).

<sup>17</sup> Loi n°2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie.

<sup>18</sup> Article 1 Loi n°2005-370 du 22 avril 2005.

<sup>19</sup> Article 2 Loi n°2005-370 du 22 avril 2005.

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<sup>5</sup> Ibid, p. 386.

<sup>6</sup> Cf. the definition of euthanasia in the Belgian Act on Euthanasia 2002, section 2.

<sup>7</sup> Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding (Termination of Life on Request and Assisted Suicide Act).

<sup>8</sup> Belgian Act on Euthanasia 2002.

<sup>9</sup> Article 2 subsection 1 Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding (Termination of Life on Request and Assisted Suicide Act).

## INTERNATIONAL ASSOCIATION OF YOUTH AND FAMILY JUDGES AND MAGISTRATES

In five US states, assisted suicide is no longer illegal for terminally ill patients with less than six months to live and who are of sound mind; at their request, doctors may prescribe life-ending medication.<sup>20</sup>

### **3. Children's right to die**

With regard to the question as to whether children have the right to die, a number of other children's rights should be taken into consideration.

As set out above, article 12 CRC . the right to be heard . provides that children have the right to form their own opinions about matters which affect them and that their views be given due weight in line with their age and maturity. In General Comment 12, the Committee on the Rights of the Child elaborates on the right to be heard. An important aspect of this right is that no age limit should be imposed and countries are discouraged from introducing age limits in law or in practice which would restrict the child's right to be heard.<sup>21</sup> Furthermore, the Committee emphasises that a child should be heard in all matters which affect him . without exception . when he is capable of expressing his own views on the matter in question.<sup>22</sup> of crucial importance is the clause that views of the child must be given due weight in accordance with the age and maturity of the child. The Committee stresses that the biological age of children should not be the benchmark, as children's levels of understanding differ due to experience, environment, social and cultural expectations, and levels of support. Therefore, the views of children should be assessed by means of a case-by-case analysis. The individual capacity of a child, as well as his ability to understand and assess the implications of a particular issue, determine his maturity.<sup>23</sup> The Committee also considers that a child, irrespective of age, should be included in decision-making processes with regard to his health, in a manner consistent with his evolving capacities. A child should be provided with information about all treatments, including the effects and outcomes of same.<sup>24</sup> Furthermore, the Committee strongly recommends that . where consent legally transfers to a child at a certain age . when a younger child is able to demonstrate the ability to form and express an informed view regarding his treatment, this view be seriously taken into consideration.<sup>25</sup>

According to article 3 CRC, the best interests of the child should be a primary consideration in all actions concerning children. With regard to the best interests principle, the Committee on the

Rights of the Child issued a General Comment in 2013, which presents an analysis of the deeper meaning of this provision. The Committee stresses that this principle refers to all decisions, acts, conduct, proposals, services, procedures and other measures which affect a child, as well as any omission or failure to act.<sup>26</sup> Furthermore, determination of what is in a child's best interests should be assessed on an individual basis and the child's personal context (age, maturity, experience), situation and needs should be taken into consideration at all times.<sup>27</sup> In order to ascertain the best interests of a child, his right to be heard is of vital importance. The Committee considers that the more a child matures, thus the more weight should be given to his views and opinions.<sup>28</sup>

The evolving capacities of children play an important role as well. Besides article 12 CRC, in which this aspect of a child's development is highlighted, article 5 CRC (the right to parental guidance) and article 14 paragraph 2 CRC (the right to freedom of thought, conscience and religion) state that the child should be given parental direction in exercising his rights consistent with his evolving capacities.

In all these provisions, the self-determination of the child is promoted and Korczak's belief that children who are competent and capable have the right to control their own lives, has been firmly incorporated into the Convention on the Rights of the Child. This leads to the conclusion that, in all matters concerning a child . including the right to die . the self-determination capability of the child should be a primary consideration.

In most of the countries discussed above, the rules and regulations on euthanasia and assisted suicide apply exclusively to adults. However, in Belgium and the Netherlands provisions specifically aimed at children are in place as a measure of last resort.

Since the Belgian Act on Euthanasia came into force in 2002, children aged 15 and older can request euthanasia if they are legally emancipated. An amendment to the Act in 2014 removed this age restriction and now the option of euthanasia is open to all minors deemed capable of understanding their medical condition and the consequences of their request for euthanasia. There are very strict rules and guidelines in place though; the child must be terminally ill, be suffering unbearably, which suffering cannot be alleviated by treatment<sup>29</sup> and the full consent of

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<sup>20</sup> California, Montana, Oregon, Vermont and Washington.

<sup>21</sup> Committee on the Rights of the Child, General Comment no. 12 (2009), CRC/C/GC/12, paragraph 21.

<sup>22</sup> Ibid, paragraph 27.

<sup>23</sup> Ibid, paragraphs 28 . 30.

<sup>24</sup> Ibid, paragraph 100.

<sup>25</sup> Ibid, paragraph 102.

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<sup>26</sup> Committee on the Rights of the Child, General Comment no. 14 (2013), CRC/C/GC/14, paragraphs 17 . 18.

<sup>27</sup> Ibid, paragraph 32.

<sup>28</sup> Ibid, paragraph 44.

<sup>29</sup> Section 3 subsection 1 Wet betreffende de euthanasie (Belgian Act on Euthanasia 2002, after amendment).

## INTERNATIONAL ASSOCIATION OF YOUTH AND FAMILY JUDGES AND MAGISTRATES

the child's parents is required.<sup>30</sup> Furthermore, an assessment must be carried out to determine whether a child is mentally mature enough to make such a pivotal decision; this is done on a case-by-case basis and the biological age of the child is not a factor. In addition to the consultation of a second physician, a third specialist . an independent paediatric psychiatrist or psychologist . must be consulted; the latter has to examine the child, study his medical file and assess the maturity of the child.<sup>31</sup>

An important argument in the deliberations on the amendment of the Belgium Act on Euthanasia, was the acknowledgement that children . however hard to accept . may also find themselves in the extremely difficult situation that life is no longer bearable and that their suffering should be ended actively, rather than passively awaiting death. Children who are confronted with life-threatening illnesses and imminent death, are known to develop a maturity way beyond their biological age, which allows them to reflect and express themselves on their remaining life in an informed manner.<sup>32</sup>

In the Netherlands, legislation allows for children to request euthanasia from the age of 12 onwards. Between the ages of 12 and 16, a physician must assess the child's competence in fully understanding the implications of his request. In addition, full parental consent is required.<sup>33</sup> With regard to children aged 16 or 17 and deemed capable of making a reasonable appraisal of their own interests, the attending physician may comply with such request without prior parental consent, but the child's parents (or guardians) must have been consulted in the matter.<sup>34</sup>

In addition, a separate protocol has been drawn up which contains guidelines for life-ending treatment of newborns who are seriously ill and suffering severely without any hope of improvement in the future. The protocol contains the following five criteria:

- the child's suffering must be so severe that there are no prospects of a viable future and there is no cure or alleviation available through medication or surgery;
- parental consent is obligatory;

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<sup>30</sup> Section 3 subsection 4 Wet betreffende de euthanasie (Belgian Act on Euthanasia 2002, after amendment).

<sup>31</sup> Section 3 subsection 2 Wet betreffende de euthanasie (Belgian Act on Euthanasia 2002, after amendment).

<sup>32</sup> Report of the 5<sup>th</sup> session of the Belgian Chamber of Representatives, DOC 53 3245/004.

<sup>33</sup> Article 2 subsection 4 Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding (Termination of Life on Request and Assisted Suicide Act).

<sup>34</sup> Article 2 subsection 3 Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding (Termination of Life on Request and Assisted Suicide Act).

- the physician has fully informed the parents regarding diagnosis and prognosis and together they have come to the conclusion that there are no other options open to them;
- an independent physician has been consulted and has examined the newborn;
- the deliberate ending of life must be carried out meticulously and according to accepted medical standards.<sup>35</sup>

Between 2002 and 2014, a total of five cases of euthanasia on minors were reported to the Review Committees. In one instance, the child was 12 years old, while the other children were 16 or 17; in all cases the child's family understood and fully supported the decision.<sup>36</sup>

The Dutch Association of Paediatrics has recently raised the issue of the applicable age limit in the Netherlands. The Association has called for the age limit to be removed, in line with Belgian legislation. For terminally ill children who are able to express their own will, the right to die should be an option and the child's opinion should be given due weight. In addition, when a child is deemed incapable of making a reasonable appraisal of his own interests, the decision on euthanasia should lie with the physician and the child's parents.<sup>37</sup> This is an elaboration of Belgian legislation, where the child's ability to express his own will is the deciding factor.

### **Conclusion**

The child's right to life is a universally accepted principle; in addition, it is acknowledged that life denotes more than just being (kept) alive and involves observance of numerous other rights. However, is a child's right to life inextricably linked with the right to die?

The right to die is best explained from the point of view that every human being has the right to self-determination and should therefore have the autonomy to decide when and how to end his life, should circumstances warrant such discussion. It is not the author's intention to advocate legalising euthanasia or assisted suicide and how this should be effected. The observations below are based on the assumption that discussion about the regulation of the termination of life of a human being is not by definition ruled out. History shows that issues about which dialogue was unthinkable in the past are now fully accepted and with this in mind, the author hopes that the reader is willing to take heed of the conclusion to this article.

The Convention on the Rights of the Child contains a number of articles which promote a child's self-determination. A child . who is capable of forming and willing to form his own opinion . should be heard with regard to all matters which

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<sup>35</sup> Groningen Protocol 23 June 2005.

<sup>36</sup> Code of Practice, Regional Review Committees Euthanasia, 2015.

<sup>37</sup> Dutch Association of Paediatrics, 19 June 2015.



## INTERNATIONAL ASSOCIATION OF YOUTH AND FAMILY JUDGES AND MAGISTRATES

concern him and his views should be given due weight in accordance with his maturity. Furthermore, when ascertaining a child's best interests, his opinion should seriously be taken into consideration. The consequences of the child's evolving capacities are such that the more aptitude a child gains, the more he should be allowed responsibility for decisions which affect his life.

Legislation in both Belgium and the Netherlands contains provisions concerning child euthanasia. In Belgium there is no age restriction, but a child must be deemed competent to fully understand his situation, whereas in the Netherlands the minimum age is currently fixed at 12 and requests for euthanasia from children under the age of 12 are inadmissible. The death of a child is one of the most devastating events imaginable and arouses immense sadness, anger and feelings of injustice. It is not inconceivable though that for a child who lives in horrendous pain and who . due to a life-threatening illness or medical condition . will continue to suffer unbearably for the remainder of his life, death could be considered more humane than sustained life.

In the Preamble of the CRC, it is recognised that a child should grow up in a family environment, in an atmosphere of happiness, love and understanding. When factors arise which interfere with these aspirations, there are safeguards in place. For instance, article 9 CRC provides that a child has the right to live with his parents, unless this is not in his best interests. In that case, the child needs to be separated from the parents and the State has to provide him with alternative care, such as a foster family, or care provided by next of kin (article 20 CRC).

When confronted with the . exceptional and extremely difficult . situation that the suffering of a child has become unendurable and there is no prospect of improvement, the child in question should also be provided with special safeguards in order to protect his best interests. If a child is deemed mentally competent, he should have the right to refrain from exercising his right to life and be given the alternative of a request to have his life ended; a child who is not capable of making such a request, should have his best interests assessed and determined by his parents and one or more physicians, who on his behalf may come to the conclusion that . as a measure of last resort . the child has the right to an end to his life.

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