Belgium Considering New Euthanasia Law for Kids

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By MARIA CHENG AP Medical Writer

Should children have the right to ask for their own deaths?

In Belgium, where euthanasia is now legal for people over the age of 18, the government is considering extending it to children — something that no other country has done. In fact, the Belgian Senate voted in favor of extending its euthanasia law to terminally-ill children in Dec. 2013 by a vote of 50-17.

The lower house of parliament passed it in February 2014, and with the signature of King Philippe, Belgium became the first nation in the world to abolish all age restrictions on the right to die, extending permitted euthanasia to terminally ill children.

Belgium is one of only three countries to have legalized euthanasia, the others being Luxembourg and the Netherlands. The Dutch also allow minors the right to die from the age of 12 with parental consent. Belgium, however, is the first to drop all age restrictions.

Advocates argue that euthanasia for children, with the consent of their parents, is necessary to give families an option in a desperately painful situation.

The law allows children to ask for euthanasia if their illness is terminal, they are in great pain and there is no available treatment. Euthanasia for children is now legal once the child has requested it and the parents have given their consent. A psychologist would have to ensure the child is capable of understanding the implications and genuinely wished to die.

The law stipulates a number of caveats on euthanasia:

- It says the patient must be conscious of their decision and understand the meaning of euthanasia
- The request must have been approved by the child's parents and medical team
- Their illness must be terminal
- They must be in great pain, with no available treatment to alleviate their distress

In November 2013, 17 pediatricians urged lawmakers in Belgium to approve the legislation in an open letter.
"Experience shows us that in cases of serious illness and imminent death, minors develop very quickly a great maturity, to the point where they are often better able to reflect and express themselves on life than healthy people," said their statement.

But opponents have questioned whether children can reasonably decide to end their own lives.

Belgium is already a euthanasia pioneer; it legalized the practice for adults (over 18) in 2002. The 2002 law governing euthanasia allows adults to choose to end their lives, if they:

- are competent and conscious
- repeatedly make the request
- are suffering unbearably - physically or mentally - as a result of a serious and incurable disorder

Between 2002 and 2012, there were 6,945 registered deaths by euthanasia in Belgium. About 80% of those who choose euthanasia have cancer. In the last decade, the number of reported cases per year has risen from 235 deaths in 2003 to 1,432 in 2012. Doctors typically give patients a powerful sedative before injecting another drug to stop their heart.

Recent cases include the January 2013 case of Marc and Eddy Verbessem. These identical twins of 45, who were deaf, asked for euthanasia after finding out that they would go blind as a result of a genetic disorder - they feared they would no longer be able to live independently.

"It is strange that minors are considered legally incompetent in key areas, such as getting married, but might (be able) to decide to die," Catholic Archbishop Andre-Joseph Leonard testified.

"The child does not have the maturity to get married or to buy alcohol or to buy cigarettes if he is 14. Now we are saying that because he is suffering, he might have the possibility to ask for euthanasia," Carine Boucher, with the European Center for Bio-ethics in Brussels, said.
Michel De Keukelaere, a law student and the founder of the March for Life in Brussels said, "Children never choose to die. I don't believe a child under 18 who is sick and who is ill wants to die."

"Who will give the suggestion to the child that one of the solutions is euthanasia?" Boucher asked. "A child doesn't know what euthanasia is. A child doesn't know what death is."

"We think that children don't understand the character of death, they don't understand the irreversibility of death," said Els Van Hoof of the Christian Democratic and Flemish party. "They are also influenced by authority, by their parents, by the medical team. So, to take a decision which is a huge decision about their death we don't think that they are capable of doing it."

Supporters of the law also weighed in heavily. According to Senator Jean-Jacques de Gucht, of the Open Flemish Liberals and Democrats, it is important "for the minors, for the capable minors, who are suffering today, and who I think should have the freedom to choose how they cope with their suffering."

"This is very important because one child that suffers is one too many," said De Gucht, who is working on the bill.

The debate has extended to medical ethicists and professionals far from Belgium. Charles Foster, who teaches medical law and ethics at Oxford University, believes children couldn't possibly have the capacity to make an informed decision about euthanasia since even adults struggle with the concept.

"It often happens that when people get into the circumstances they had so feared earlier, they manage to cling on all the more," he said. "Children, like everyone else, may not be able to anticipate how much they will value their lives if they were not killed."

There are others, though, who argue that because Belgium has already approved euthanasia for adults, it is unjust to deny it to children.

"The principle of euthanasia for children sounds shocking at first, but it's motivated by compassion and protection," said John Harris, a professor of bioethics at the University of Manchester. "It's unfair to provide euthanasia differentially to some citizens and not to others (children) if the need is equal."

And Dr. Gerlant van Berlaer, a pediatric oncologist at UZ Hospital Brussels, says the changes would legalize what is already happening informally. He said cases of euthanasia in children are rare and estimates about 10 to 100 cases in Belgium every year might qualify.

He was one of the 17 Belgian pediatricians who signed an open letter in November 2013 petitioning senators to vote for the child euthanasia bill.
Van Berlaer stresses that only a tiny number of children would ever choose to end their lives this way: children with cancer, for example, who are still in charge of their cognitive faculties but in terrible pain.

"Rarely - but it happens - there are children we try to treat but there is nothing we can do to make them better. Those children must have the right to decide about their own end of life," says Dr Van Berlaer.

"We are not playing God - these are lives that will end anyway," argues Van Berlaer. "Their natural end might be miserable or very painful or horrifying, and they might have seen a lot of friends in institutions or hospitals die of the same disease. And if they say, 'I don't want to die this way, I want to do it my way,' and that is the only thing we can do for them as doctors, I think we should be able to do it."

Experiences in the Netherlands, where patients older than 12 are allowed to request euthanasia with their parents' consent, would seem to support this: Only five children have chosen to die by euthanasia since the law was introduced in 2002.

Polls show the majority of Belgians agree with the principle of offering euthanasia to children.

Case of Ella-Louise

As little Ella-Louise faded away, her tiny, frail body wracked with pain, her heartbroken mother was left to look on, feeling powerless.

Linda van Roy says she could do nothing to help her terminally ill baby in the last hours of her life.

"In that period, they tell you it's best not to give any fluids, because babies survive on little drops of liquid," she said. "So we stopped feeding her. In the end, it was bones and skin and no more baby left."

Ten-month-old Ella-Louise died in 2011 with Krabbe disease, a rare and terminal genetic mutation that damages the nervous system.

In the final days of Ella-Louise's life, when she was being given palliative sedation, van Roy, of Schilde, Belgium, says she could still see the agony on her daughter's face.

"She died on Tuesday; on Monday, we saw on her face that she was still in pain. And then you start to get angry, because you know that there is no medication left to give her to take away that pain."

She wishes she could have administered a fatal dose of medication to make the end of her daughter's short life come more quickly.
Under the current rules, the patient must be able to make a repeated request for euthanasia themselves while experiencing unbearable suffering of which there is no prospect for improvement.

But van Roy believes that children, and parents of sick babies, should have more options, including the right to choose when to die.

"We want those children to be able to talk about euthanasia, and if they really want to say: 'Stop, this is it. I don't want it anymore,' we want people to have a choice," she said.