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Auteur	Charlotte McDonald-Gibson
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‘Babies don’t need to die like this’: The argument for child euthanasia

The right-to-die debate has gone a step further in Belgium. Charlotte McDonald-Gibson speaks to a mother who wants others to avoid her baby’s slow, painful death

Mementos of Ella-Louise’s short life fill a cosy corner of the Van Roy household. There are tiny footprints in messy paint; framed photographs of the baby girl with a proud older brother; paper butterflies representing the beauty and fragility of Ella-Louise’s 10 months with her family.

But this mantelpiece display of warmth and love is not all Ella-Louise’s mother wants people to see. As Belgian politicians debate a proposal to amend the country’s euthanasia laws to include children, Linda Van Roy also wants to share her child’s final days. “I’ll show you how my daughter was and what she became – you will see why I want to speak up,” she says, opening a book of photographs.

The amateur snaps show Ella-Louise as a tiny newborn in the arms of her parents, her face slowly changing as the months pass by; her eyes dulling, her mouth contorting, her tiny hands clenching into fists, her cheeks burnt from repeated vomiting. But it is the last week that her body transforms, her legs wasting away, her skin turning a dusty pallor.

“This is what was left of my baby and that is why I want to tell my story, to make sure that babies don’t need to die like this, that parents don’t need to see this,” says Ms Van Roy.

Ella-Louise had an incurable genetic disorder. Her death at such a young age was inevitable – what Ms Van Roy wishes had not been inevitable was her suffering in the final days of life. That is why she is arguing in favour of amending the law to make Belgium the first country in the world to legalise the euthanasia of children of any age in cases of unbearable and irreversible suffering.

It is an emotional debate for everyone involved, with persuasive arguments on both sides. Opponents say that the 2002 law which made Belgium the second country at the time to legalise euthanasia led to abuses and a cavalier attitude towards life and death. “The slippery slope that we have seen with euthanasia in adults will also occur in children,” says Dr Benoit Beuselinc, an oncology specialist at the University of Leuven.

But other doctors believe that in some cases, terminally ill children have the maturity to make life and death decisions about their treatment, and should be afforded the same respect – and legal rights – as adults in the same circumstances.

“Once in a while we have some situation... when the child is asking for [euthanasia] and you know this child is really, really capable of making this decision, then it’s very awful when you can’t do anything,” says Joris Verlooy, a Belgian paediatrician practising in The Netherlands.

Not every child, however, is able to speak for themselves. Ella-Louise was five months old when Ms Van Roy noticed she was having trouble swallowing. After a week of tests, the doctor told Ms Van Roy that her daughter had Krabbe disease, a genetic disorder which affects the nervous system. "He explained everything about DNA and said that the conclusion was there was nothing else they could do to cure her and the only thing that we could do was to make sure that she was in no pain and to make everything as comfortable as possible," says Ms Van Roy.

And so that's exactly what Ms Van Roy, her husband and their young son did, nursing Ella-Louise at home and making sure she was surrounded with as much love, warmth, and comfort as they could provide. When Ella-Louise kept pulling the feeding tube out of her nose, they asked the doctors to put one directly in her stomach. When the Valium used to control the pain and tension in Ella-Louise's limbs started to wear off, they switched to morphine. When the disease attacked her jaw and Ella-Louise was unable to close her mouth, they used a balm to try and relieve her discomfort. Then Ella-Louise started to throw up all the time, and Ms Van Roy knew there was not much more they could do.

"There is a little baby that is lying there, who is not reacting any more, who is not looking at you any more, who is not responding any more, then as a mum, you know that it is finished," she says. "You are keeping a body alive, but there is no child any more."

But as parents determined to ensure their daughter died with as little pain and as much dignity as possible, there were not many options open to them. Belgium's euthanasia law applies only to adults who are able to express a desire to end their lives. A legal text known as the Groningen Protocol which shields doctors from prosecution in rare mercy killings applies only in The Netherlands.

The only option open to the Van Roys to control Ella-Louise's suffering was palliative sedation, legal in many countries including Britain, in which high doses of sedatives are prescribed at the very end of a person's life. The doses are not permitted to hasten death, but when food and liquid are withdrawn and palliative sedation begins, it is usually hours or days before the patient dies.

Ella-Louise began taking the sedatives on Tuesday, 15 November, 2011. The first few hours were a relief for Ms Van Roy. The drugs made Ella-Louise relax, and family members were able to say goodbye. The doctors said the end would come in a few days. But the days passed, and although her body was getting weaker and thinner, Ella-Louise's heart kept beating.

One of the arguments against liberalising the euthanasia law is that palliative sedation is enough to relieve the physical suffering of children with terminal illness. But after a week of watching her daughter waste away, Ms Van Roy disagrees: "It took too long. You're not giving any fluids to the child, she was really very, very skinny when she died. The Monday before she died, you saw the pain coming back on her face."

Ella-Louise's case illustrates one of the issues at the heart of the child euthanasia debate. Should there be an age limit so it only applies to children who are old enough to ask for the right to die? In the Netherlands, children between the ages of 12 and 16 can request euthanasia, but it can only be carried out with their parents' permission. Indications are the Belgian parliament will back a similar change in the law.

Dr Verloy argues against an age limit, and says the law should allow doctors, parents and other carers to make decisions on a case-by-case basis. Gerlant van Berlaer, a paediatrician at the University Hospital Brussels, thinks it should be broad enough to cover babies born with such debilitating disabilities or illnesses that they have no decent quality of life.

Such vague parameters concern some doctors, who point to cases in which Belgium's existing euthanasia laws have arguably been applied incorrectly. While Belgians overwhelmingly support the current euthanasia laws, some cases have provoked debate. Last year, Marc and Eddy Verbesssem – twin brothers in their early 40s – requested euthanasia because they were both deaf and were slowly going blind. Although neither had a terminal illness, their request was granted.

“Euthanasia has been applied to patients with chronic depression or with the first signs of blindness or Alzheimer’s disease – these patients are not treated any more, they just receive a lethal injection, says Dr Beuselink.

Religious groups, meanwhile, argue that doctors should not have the power over life and death. “To say no to euthanasia is to recognise and take care of this inner sanctuary that makes a human being a human being,” a former hospital chaplain wrote on the Belgian website, euthanasiestop.be.

Despite vocal opponents, the debate over child euthanasia has been restrained and respectful in Belgium, where euthanasia now accounts for two per cent of all deaths.

Jan Bernheim, an expert in palliative care who helped draft the 2002 euthanasia law, says it has led to a decrease in abuses or questionable decisions because now it is regulated and openly discussed. The same positive legal oversight would apply if euthanasia for children was legalised, advocates say. Mercy killings of terminally ill children do already take place in Belgium and elsewhere, doctors say, but because they are technically illegal these decisions are made under a cloud of fear and secrecy. “The law liberates – it’s a beacon and it obliges everyone to pay attention to that beacon,” says Dr Bernheim.

Belgian doctors, religious figures and campaigners presented their arguments to a Senate Committee before the government went on their summer recess. Also being considered is an amendment that would allow patients in the early stages of dementia to request that they be euthanised when their condition deteriorates. At the moment, they need to be “of sound mind” at the time of their deaths. No agreement was reached on either issue, and the debates are set to resume next month.

Dr van Berlaer wants opponents to understand that no doctor would take a life or death decision involving a child lightly. He recalls the first time he was confronted with the issue when working at a Dutch hospital a decade ago. A 12-year-old boy had stopped breathing, and as Dr van Berlaer struggled to resuscitate him, the child’s parents asked him to stop. They said the boy was suffering his third recurrence of cancer, and had lost any joy in life. “I was still thinking of what to do in this particular case when his nine-year-old sister came to pull my sleeve and said ‘doctor, the only thing good you can do for my brother is stop what you are doing’,” says Dr van Berlaer.

Finally he stopped the resuscitation and watched the child slip away. “We are just trained to preserve life at any price,” he says, but sometimes, “you feel it is simply not the right thing to do”.

Right to die: Around the world

Switzerland

Assisted suicide has been legal since the 1940s and is a crime “if and only if the motive is selfish”. Uniquely, it allows assisted suicides to take place at home without a doctor present, and the recipient does not need to be a Swiss national. All assisted suicides are video-taped and verified by police.

Netherlands

Patients in “unbearable and hopeless” suffering have been permitted to end their lives since 2002. Doctors must make their case before a review committee.

Luxembourg

It became the third country to allow euthanasia in April 2009 with legislation that protects doctors as long as they first consult a colleague to ensure that the patient has a terminal illness, is in a “grave and incurable condition,” and has repeatedly asked for the right to die.

US

Four states in the US allow euthanasia. The first was Oregon, which passed a law in 1994 allowing physician-assisted dying. The law was upheld by the Supreme Court in 2005. Washington, Vermont and Montana have also passed laws allowing euthanasia.