

ONDINE'S LIFE

Véronique Fournier – I want to tell you the story of a little girl, who was born a few weeks ago. I'll call her Ondine for the time being, because she was born with what is known as Ondine's disease, a very strange disease. Like in Giraudoux's play, Ondine's curse consists in forgetting to breathe when you fall asleep. So falling asleep means dying because you're no longer breathing. Nowadays, a number of children are born in places with intensive care doctors and a lot of technology, so we can resuscitate them immediately. That's how we noticed why they died: once they'd come out of their mother's womb and had a good scream, they fell back asleep to rest and that's why they died. Gradually, we realised that we had to ventilate them artificially for them to survive. So for the past few years, the medical profession has been very proud of itself for enabling these children to survive! And it believes they survive very satisfactorily because their development is absolutely normal and they are otherwise just like you and me. They are perfectly well and lead a completely normal life, provided that they learn to plug themselves into a breathing machine every time they fall asleep.

A few weeks ago, when she realised what was happening to her small daughter, Ondine's young mother begged the medical profession to stop giving her this breathing machine, saying: What kind of life is this I'm offering my daughter, I don't want that kind of life for her! You no longer realise how strange it is to breathe with a machine. You intensive care doctors think it a great progress that medicine can offer this. But I can't see myself answering my little girl's questions in a few years' time, like: Why did you let me live in these conditions? I can't imagine giving her a life that wasn't what I wanted for her, with this massive thing happening to her all her life. And the team said: Stopping the treatment is out of the question, since we know we can save her now.

In the Centre for Clinical Ethics, we were caught up in this conflict, as doctors and researchers. It's very interesting. On the one hand there are doctors who no longer really realise what they are offering and, what is more, who do it with a clear conscience, to provide what they consider to be a good life. And on the other hand, civil society members completely understand the mother's position and say: Just because medicine can do something, should it be done? At what point are we crossing lines? This question of when lines are being crossed in medicine is an absolute torment for us. In the end, who should decide whether this little girl's life is worth living, with this treatment burden? Should her mother decide, should the doctors? That's an extremely difficult question to answer. Many people are probably very grateful to medicine for the progress it has made, including people who have been living with Ondine's disease for the

past few years or even decades now. Four to five children are born each year in France with this disease, which can either be “not serious” in inverted commas, meaning that this breathing problem is all that happens to them, or much more serious. And yet even in the “not serious” cases, the burden of technology they depend on is still huge. That was the story I wanted to tell you.

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