

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Critical Care Decisions in Fetal and Neonatal Medicine: Ethical issues during March to June 2005. The views expressed are solely those of the respondent(s) and not those of the Council.

Anon 9

I would guess that my views on treatment are not those of an average person (if there is such a thing as an average person!!!), but they are based on real life experience.

About ten years ago my wife had some pretty serious periodontal disease, and the specialist operated on her gums. This worked pretty well, but for many years following that my wife spent between an hour and an hour and a half each night cleaning her teeth. This has now reduced to between fifteen and thirty minutes. About a month ago I went to see our local hygienist who told me of my gum problems, and she was keen for me to do all sorts of extra procedures to rectify this. I told her that I would rather lose my teeth, than spend my life looking after them – the teeth are there to serve me, not the other way round. It was the first time she had heard this sort of response, although no doubt she had come across plenty of folk who said they would do all the extra things, but never did.

Almost exactly five years ago, my wife was diagnosed with myeloma. The specialist expected that without treatment she would die within a year, but with treatment they hoped to give her up to five years of life. They also spoke of quality of life and hoped that she would have an eight out of ten life after treatment. The treatment was chemo followed by a bone marrow transplant, when my wife received her brother's stem cells. In terms of the cancer the treatment was a great success, as there has been no sign of it for over four years. But it has taken four years so far for her to recover from the treatment, and she still hasn't got over it. Her quality of life is probably at nine out of ten, so she probably rates as an outstanding success as she is not in any sort of life threatening condition right now. Losing that one out of ten is significant, and my wife has been through some pretty ugly and undignified times to get to where she is now. I am really grateful to the outstanding attention she has received from the NHS, and I am well aware that she has cost the NHS some pretty serious money over the last five years and everything is wonderful, except my feeling is that if I am diagnosed with cancer, I will not undergo any major treatment for it.

In terms of prolonging baby's lives, I would say that if there is a reasonable chance of full recovery, then there is every reason to go for it. But if the treatment is only delaying the inevitable or may leave any sort of loss of quality of life as its legacy, then that treatment should be withheld. But I know that making the decision at a distance is a whole lot easier than having to make that decision for a case that you are involved in. And discussing it with the families is also a mighty big task. And if I were the parent at the sharp end of one of these decisions I don't know if I would be as certain as I am now.