Inquiry into End-of-Life Choices

1. Introduction

My name is Beverley McIntyre and I wish to make a submission into 'Inquiry into End-of-Life Choices'. My contribution is based on the time immediately preceding my partner's (Rudi Dobron) death on 1st December 2008 – in particular the experience of palliative care.

Following discharge from hospital Rudi was referred to palliative care. In hospital he had received treatment for carcinoma of the larynx followed by the oesophagus – radiotherapy, approximately six lots of surgery and then 'palliative chemotherapy' – the last being disbanded after four doses due to a bout of pneumonia. So already he was having trouble communicating (usually by writing) and swallowing even before the chemotherapy was terminated.

2. Introduction to Palliative Care

Two palliative care nurses visited him at home. One asked him was he afraid to die and he replied "not of dying but the way I die". He was then assured that he would be given drugs and "out you go". The first piece of unreality.

The first visit a week's respite in palliative care hospice was recommended " to review his medication". When booking the nurse informed them that Rudi had completed both P of A (power of attorney) and AHD (advanced healthcare directive) forms. These were handed to the doctor on admission. This was on 15th October 2008 and for the first week he could cope mainly with soup and ice-cream.

3. End of the First Week in Care

By the end of the first week he refused all food and drink and for the rest of the five and a half weeks only rinsed his mouth with soda water, spitting it out. The treating doctor on every visit offered artificial feeding by means of a tube through the stomach (PEG), which Rudi refused. It was alternatively suggested that he could return to hospital for a dilation. This also was refused by him as he was tired of hospital procedures, which he thought would only prolong his life. Although "nil by mouth" was on his bed termination of the daily production of a menu had to be requested.

4. Some Extracts from the Medical File, Which was Obtained Following His Death

24/10/08 Unable to eat or drink
26/10/08 Wants to be sedated
27/10/08 Wants to die - "no quality of life"
30/10/08 Does not want "life-prolonging measures". Worried about choking - "scared look in his eyes".
02/11/08 He was assured catastrophic orders were in place.
08/11/08 Unable to use mobile as hands weaker
11/11/08 Partner reassured by the treating doctor "his comfort our priority" and that there were plans to deal with the catastrophic event and "we would sedate him so he was not aware".
15/11/08 Hallucinations - "lots of insects crawling up the wall". Partner was reassured there was medication on hand to deal with hallucinations but the hallucinations continued. "Terminal agitation" was also noticed. On one visit it was noted that he attempted to get out of bed. Other times trying to undress and take his bedclothes off.

5. Note

Before Rudi had to give up writing because of weakness he wrote a note:

"I am dying of cancer of the throat. I can no longer control my bowels nor eat or drink. If I was a pet I would have had a peaceful injection days ago. But I am human and so I will have to go through the barbaric religious ritual of dying without dignity from dehydration over weeks..."

6. Death and After

Rudi died on 1st December 2008 having spent six and a half weeks in the hospice altogether. He was not responsive during the last week. The forms P of A and AHD were <u>not</u> in his file.

Caritas Christi is a pleasant-looking hospice and Rudi was lucky to have a room on his own but it was discovered by a medical specialist who perused the file that he was administered a grossly inadequate supply of morphine and other drugs. These could have made his long, drawn-out death a little more bearable and could have meant his frequent requests for his life to be shortened perhaps more possible. They could have relieved him of some of the pain, suffering and indignity when the only option left to him was dying by starvation and dehydration.

In his file was "he died comfortably"!

7. Discussion

Some people say palliative care needs more money. Instead, or as well as, the philosophical, religious and legal issues should be addressed in a rational way. The palliative care staff seemed to be reluctant to administer appropriate drug doses because of these unanswered concerns. In these matters possibly they believe they may be open to legal charges although the Medical Treatment Act of 1988 states (f) "to ensure that dying patients receive maximum relief from pain and suffering and the AMA Code of Ethics (1.4) (c) "Respect the right and severely and terminally ill patient to receive treatment for pain and suffering even when such therapy may shorten a patient's life".

It is time that the public, who is seems would vote in favour of PAD (physician assisted dying) deserve a change in the law (75-80%) has a say instead of these decisions left to politicians who would either vote in a bloc or "according to their conscience".

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