

Assaulting the Dying

Ruth Johns

I thought I was clued up about death. Having helped professionally with bereaved people; having cared for loved ones when dying; having experienced severe pain and the probability of dying myself; having no hang ups about religiosity: I learned to feel comfortable with the cycles of life including death.

But, even so, events recently created a fear. However much we cooperate with the needs and wishes of someone who is dying, we may be helpless to prevent their worst nightmares from occurring. And, like Paula, they may not be able to protest.

From 1980 until a year ago, Paula had a granny flat in our home. Over twelve years, we became the ever busier unseen hands who did the back-up which allowed 'independence'. But last year a complicated fracture following a fall found her, aged ninety-one, in hospital. In spite of successful surgery, she was left severely immobilised and needed 24-hour care. After much searching, we found a small, friendly, affordable rest home two miles away. She had an en-suite room. We visited every other day at least. One of the reasons this home was right for Paula was because people were allowed to stay when ill and were not hospitalised to die. Paula feared institutions. This was not irrational: her father was murdered in a concentration camp.

She failed to adjust to being so handicapped. Had she been able to adjust to increasing frailty, she probably would not have fallen. She refused ever to take reasonable care. Once severely handicapped, she decided she had had enough life and announced daily that she 'wanted to go'. To this end, she began to stop eating and drinking. Only once during the sixteen years I knew her did I rage at her. And this was to command that, whatever her ideas on life and death, she should continue taking liquids so that both would be comfier. She obeyed.

After some weeks of depression at her immobile state (and I believe the weight of her past experiences which she never could discuss with anyone), she became calm. Occasionally, a glimpse of humour returned. Then, she began to slip away. For a couple of days she stayed in bed and slept. Her kidneys began to fail. Matron knew she was dying and her staff, and we, were making her comfortable. We felt relieved that Paula's wishes were slowly and very peacefully and painlessly taking shape. We left temporarily as I had to have treatment for a muscular condition.

We reached home an hour and a half later to hear matron's message on our answerphone. Paula's GP had phoned the rest home to say an ambulance was on its way to take Paula to hospital three miles

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away. Paula was no longer well enough to talk, but she struggled as much as her strength would allow as the ambulance crew lifted her from her bed, sat her in a chair, took her into the cold night and into an institution with bright lights, noise and white coats.

We rushed up to the hospital and into the ward. We could not see her. There was one curtained cubicle. My husband was silenced through shock. I asked if she was inside and was told to go away and wait. I demanded politely to see the doctor in charge, and was told to go and sit and wait. There was a team of people in the cubicle preparing to do investigative procedures. Paula sounded distressed. I then demanded that we should be seen straight away, and the house doctor emerged and led us to an anteroom.

At first, he kept reiterating the case for medical intervention. Then fortunately, he listened to us and to Paula's wishes. This took some time. He then phoned the consultant in charge who fortunately agreed that they would simply make Paula comfortable. And she was made comfortable, lying in bed in exactly the same way as she had been before being cruelly kidnapped. Paula knew we were there though she could not talk. She relaxed

and died very peacefully a few hours later.

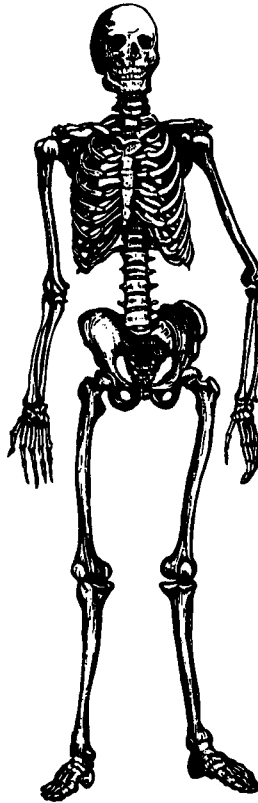
Matron was upset. She did not like a resident being 'snatched'. We felt terrible.

We were told by the hospital staff what would have happened had we not arrived when we did, and had the consultant decided differently. The minimum treatment Paula was about to have were painful internal investigative procedures and, of course, drips. And quite probably a lot more because 'more problems were suspected'. When we collected the death certificate from the ward the next day, nursing staff said how distressing it was that so many very old people suffered so much intervention when all they wanted was, like Paula, 'to go'.

Afterwards, we were left wondering how this could have happened to Paula. Her GP knew her background, so we had assumed (wrongly as it turned out), that her own views would

be respected. We sought an explanation. It is routine when someone in a rest home is very ill for a doctor to be called. If you die without seeing one, you have to have a post-mortem. The blood test the GP had taken showed renal failure, and the 'usual clinical response' to this was what happened.

After a long discussion with her GP, we realised that Paula had been hospitalised



in the middle of her dying in case her relatives (us) sued, claiming 'everything had not been done to save her'. To save her from what?

It became clear, in our interview with Paula's GP, that in such a circumstance, the rest-home matron (who is a very experienced SRN) could be overridden. So could we had we been there when the ambulance arrived. The GP's 'clinical judgment' is paramount: and yet this is based on fear of relatives' reprisals. Even had Paula made a living will, we were told a doctor's judgement was paramount as the law stands at present (though I know many doctors do take heed).

At best, with intervention, Paula might have been 'brought back' for a very short while, with much physical discomfort and a horrendous amount of psychological pain.

My questions are these:

- 1) I realise there may be times when it would be very hard for a doctor to know a patient's wishes. But, should not all GPs who are attending the very elderly know, as far as is humanly possible, what the wishes of each person may be in the event of this type of situation and take these wishes into account? There are very elderly people who would go through any pain and medical intervention even for a few extra days. Most, however, would simply prefer care, love and comfort in their dying. Taking their wishes into account must surely be part of clinical judgement. If not, what is the meaning of 'community care'?
- 2) Is it not brutalising ambulance crew and hospital staff to insist they cause suffering when their instincts and training

are to prevent it? The ambulance crew, we were told, were very distressed at having literally to wrench Paula, when she was dying very peacefully, off her bed and out onto a cold journey. If I was a doctor, I would not feel right giving a rigorous internal examination to a dying woman of ninety-two against her wishes. This is surely assault. I am so glad we were just in time to prevent this.

3) Paula's dying cost the NHS a lot and, had she been able to talk, she would not have said thankyou. She had a sense of the right time and place for medical care: she was an auxilliary nurse for many years in a psychiatric hospital (which, yes, was quite compatible with her fear of institutions). Is it not irresponsible that NHS costs are incurred in hospitalising very elderly dying people against their wishes, thus misusing finite resources as well being inhumane?

