



Dear Readers,

Outside there is deep snow; a bit unusual and unnatural at this time of the year. Inside, we are busy packing the contents of our house and preparing to move again. This time to Basle, Switzerland. It is also a good time to reflect on the past six years spent here in the UK. When I moved here in 2005 from The Netherlands, I had a couple of goals I wanted to achieve. The first was that I wanted to work in my specialty of Palliative Medicine in a well-organized system, where my specialty would be well integrated into mainstream medicine. Another goal was to be able to conduct some research. I had a lot of new ideas for studies and wanted to “prove” things I have been teaching to students all my life. The third, not unimportant, was to earn a decent living for myself and my family, without too much of the stress and pressure I had experienced during my work in The Netherlands, at Hospice Rozenheuvel.

I admit my expectations concerning the integration of palliative medicine in the UK were high. There is a long tradition of hospices and palliative medicine in this country, but a policy of having consultants in palliative medicine in each hospital was also fuelling these expectations. I worked for six years in hospices which were charities, and were not part of the huge National Health Service (NHS). This was good from the point of view of funding, as charities in this country have a lot more money and freedom to spend this money than their counterparts in the NHS. This is nice, as we can pay special attention to particular, complicated patients and their families and provide more personalized care. However, the beneficial financial situation of the hospices has created an unusual inequality. Once in a hospice, patients do not want to leave; “it is so nice here...” they say. Many patients admitted in an acute state improve and need to be discharged home or to other continuing care facilities. None of them liked this idea, not least because the other facilities, frequently of lower quality of service, cost them a lot of money, while traditionally hospice care is free. So, true integration within the system is seriously hampered. Patients are “malingering” and trying to stay in hospices as long as possible. They are frequently traumatized by discharge decisions and this is not pleasant. In general, I thought that the long tradition of hospices in this country would help people to overcome the barrier of the “house of death”, so obvious in Poland or in The Netherlands. Nothing like this is true. Patients do not want to go to a hospices in the UK; they do not even wish to go there to attend a clinic, because they associate it with terminal illness, deterioration and death. Many patients referred to me by hospital consultants never came to see me in the hospice, being probably afraid that it would instead “accelerate” their disease rather than help. Hospital consultants are more pragmatic in this country and once they had noticed that we provided good quality services, they started referring their patients to the hospice. It was not the same with the General Practitioners, however, as they are, in this country, slightly set aside by the specialist Macmillan nurses who deal with terminal illness. The GPs just do not have enough experience in dealing with these problems. They also seem uninterested in these issues, as are many other passionless people working in the NHS.

In general, after my experience of health care in the Netherlands, I rate the quality of NHS care rather low. I would not, personally, like to be treated in a British hospital. This is also reflected by the much worse survival rate of cancer patients in comparison with many other European countries. All this should be measured against the high costs of the NHS. For example, one of my patients was referred by us to an orthopaedic surgeon for a hip operation (a dynamic screw procedure) because of massive bone metastases from breast cancer. She was well pain controlled when she went to hospital. The operation was performed excellently, but they forgot to continue the pain treatment initiated by us. The patch, which should have been in place for four days, remained on her skin for ten. Nobody noticed this, despite our clear referral letter. Nobody

bothered to give other painkillers either. It seems that they concentrated instead on mono-specialty treatment and were unable to look outside this narrow box.

Another point to consider was the possibility of conducting research. European regulations aimed at the protection of patients preclude nearly every type of research. One of our students wanted to conduct a small study on the changes in the sense of taste in terminally ill patients. The study included a number of taste tests with cotton wool dipped in different solutions. Our hospice was asked to take out additional insurance because of this study which would have cost us 5,000 pounds. Studies with traditional drugs, so interesting and innovative in palliative care, are virtually impossible because of such costs. The only studies with new drugs possible are those instigated by the pharmaceutical industry, which pays for all costs and manages all the paperwork. Additionally, hospices can earn money conducting these studies. However, these are exactly the studies which I did not want to do, as the new drugs proposed by the industry are not only expensive in their use in the future, but are also frequently no better than the older and cheaper alternatives. Some of the new drugs virtually "demoralize" the doctors and change their practice. They are "so good", that the doctors do not need to search for a pain diagnosis. This kind of treatment results in much higher costs and only temporary relief. Being a charity also means less contact with the universities and no help in setting up trials and protocols. So, for all my six years here, I have not conducted any studies, nor have I seen others doing so.

The third, minor point was earning a decent living for me and my family. Yes, this point had looked attractive at the beginning. However, the British government has borrowed so much money over the last three years that the value of the British Pound has nosedived and still remains very low in comparison with other currencies. For me, this has meant a much higher cost of living and less income.

In fact, you could say that I did not succeed in realizing any of my original goals. So, what took me so long to realize this? Were there other, compensatory, pleasant and positive points which made me happy? Yes, there were! I worked with dedicated and pleasant people; a good professional team, which was willing to look individually at each patient and was willing to walk "the extra mile" for a good cause. Although some of the nurses were resistant to all changes, the majority were very happy with the new drugs and procedures I introduced. I hope they will not stop using them when I leave. I was impressed by the apparent rigidity of the system, concerning us in the hospice as well, in regulating small things and making truly creative solutions to problems impossible. However, I adapted to this and was not as bothered as much by this as some of my colleagues. All the time I have worked here, we have had a shortage of doctors willing to work with us and pursue a career in palliative care. The doctors' market has simply "dried up" and we were very dependent on overseas doctors from The Netherlands, Iraq, South Africa, New Zealand, Poland and Germany, who were willing to improve their knowledge and experience in palliative care. All of them were fine and well-trained colleagues. There were moments with the six of us sitting around the table when only one or none was a Briton. This created a peculiar situation and, of course, communication problems.

So, what kind of feelings do I have about leaving here? First of all, gratitude for the friendship I have experienced here and the feeling that I have managed to change something for the better. I have experienced the gratitude of hundreds if not thousands of patients and their families. I learned a lot myself and became aware of many things that I still need to learn. However, I am also happy to leave some of my problems behind and experience a new challenge. This is probably pre-programmed in my genes and has nothing to do with The System. Can hospices be improved in the UK? Certainly, yes, but it will be difficult because the NHS is in huge turmoil and disarray. Being an island of quality in a sea of mediocrity will not help our patients.

By the way, my email address will change very soon to: ben.zylicz@hildegard-hospiz.ch

Regards,

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