

So that people do not die on waiting lists

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Modern medicine can be fascinating, and organ transplantation is one of its most amazing disciplines.

But what does transplantation mean for the patient? I am sitting in a conference room in the Martin's Hotel in Brussels, at a seminar on organ donation and transplants. I am listening with great interest to Emily Thackray from the United Kingdom. She is the head of the Live Life Then Give Life organisation, which helps patients. This energetic young lady with an attractive, full figure has herself undergone a lung transplant. She talks to us about it with the help of some photographs.

Two years ago she was a scrawny, pallid creature attached to a breathing machine. Tubes trailed from her nose into a portable machine and her face carried a sad, careworn look. As a child she had cystic fibrosis, a serious lung disease that had a terrible effect on her health in general and, most seriously, on her ability to breathe.

She describes how she was exhausted and desperate. The illness was imprisoning her in her own body. It is hard for anyone who has not been in her situation to understand the major effort involved in something as simple as taking a few steps from the bed to the toilet. Eventually, her only hope was to have a transplant.

While she was waiting, people from organisations such as hers tried to help her. They wanted to ensure she did not feel alone and to help her deal with her problems more effectively. The lung transplant was successful. Emily is now married and helps people with similar medical conditions to her own. But that is not all. She organises collections, supports research and devotes herself to a large number of charitable activities. Once she had freed herself from the tubes and machines, it was as though her life had gained a clear direction, a new worth and a different meaning. When she finished her presentation, the journalists and experts in attendance applauded, as did those working in the field of transplantation for the European Commission's Health and Consumers Directorate-General, who organised this seminar.

A better life for less money

When a motorbike overtakes my car dangerously, I sometimes cynically quip to myself "Organ donor". The truth is that finding sufficient suitable donors has become a problem. This limits the number of heart, kidney, liver, lung or pancreas transplants. "Furthermore, [demand] is increasing because people are living longer and have more health problems," says Dr Pavel Březovský, MBA, head of the

transplant coordination centre in Prague. "Many patients do not live to see the organ for which they are waiting."

European countries are therefore trying to improve the process involved in obtaining such organs by amending laws, educating specialists (who actively look for possible donors in hospitals) and explaining how perfectly healthy people can donate a kidney to help those affected. People usually live several years longer when the kidney comes from a living donor than when it comes from a donor who is no longer alive. In the former case, the burden of transplanted tissue is smaller because the organ is outside the body's circulation for only about 15 minutes. "Transplantation enables patients to lead far better, more normal and, most importantly, longer lives than with dialysis, to which they must be attached several times a week," says Dr Březovský. "It also works out around three times cheaper than when a patient lives on dialysis and their health problems are treated continuously."

As though reborn

Markéta Filippová's heart problems began with a bout of the flu. She ended up in hospital, where a myocardial inflammation was detected. Other infections worsened her condition. It was a strenuous sporting feat to go upstairs in the building where she lived, to go out of the house to take a delivery from the postman; not to mention the domestic chores. Today she knows that it was only a matter of time before she would have given up completely.

Doctors believed that her situation was serious but did not believe it would become critical. At that time her heart was working at only 18 % of its capacity. Markéta wrote to Professor Jan Pirk at the *Institut Klinické a Experimentální Medicina* – IKEM (Institute for Clinical and Experimental Medicine) in Prague, who examined and helped her. She went for an operation almost immediately. They attached her to an artificial heart, which gave them the time to look for a suitable donor, one with the highest number of identical characteristics to her, most importantly in terms of blood group and antibodies. After the transplant, patients have to take immunosuppressive medicines. This is to protect the patient from the presence of foreign tissue in the body. The greater the similarity to the patient, the more effectively the immune response is suppressed.

Markéta, who was lying in hospital, lived to see the long-awaited heart and the transplant went well. She began to live a near-normal life. She now goes for walks without difficulty with her husband and their dog, both of whom she missed terribly when she was infirm. "I can now do sport, look after the house, go to work and simply do more or less whatever my laziness will allow," she laughs. She is still alive thanks to the heart transplant, and now leads a life that is following a totally different path to the one she had expected.

Everything must be bang on time

Transplants are a burden in terms of law, logistics and medicine. When doctors find a suitable donor, they get down to work with a team of specialists. They remove the required organ, store it in a special box and usually take it to another hospital, to which an ambulance takes the patient who has been waiting for the organ for months. Then they embark on their operation.

Doctors in the Czech Republic are being helped by what is referred to as 'presumed consent'. This enables them to have at their disposal any suitable organ from a deceased person, apart from those who do not wish to donate and have that wish entered in a specialist register. "In many European countries doctors have to seek the relevant consent," explains Dr Březovský, "in situations, moreover, that for the people concerned are tough and often tragic."

The Czech Republic is trying to improve the process of finding suitable donors by educating specialists to do this work. Such specialists work mainly in large hospitals. It is important that their work bears fruit because organs from one donor may save the lives of up to seven people.

There is no shortage of things we have to improve, and this is true of most European countries. "The EU institutions mentioned earlier are attempting to ensure that the level of patient care in individual countries is gradually approximated, that the all-important 'rules of the game' are applied across the board and that, as far as possible, the experience of the most successful countries is harnessed," says Dr Březovský.

Mrs Ružena's gift to Mrs Ružena

Kidney stones, inflammations and chronic disease destroyed the kidneys of a friendly 60-year-old lady. Mrs Ružena's kidneys gradually stopped working. She wrote to her doctor about the possibility of a transplant, but she was told that she was no longer the right age. She was barely 60. She went onto dialysis, and lost 30 kg in a year. "I weighed 50 kg, I lost my hair and my bones rattled," she recalls. Mrs Ružena has a daughter, who decided to help her mother at all costs. After a number of telephone calls – and then chasing up those calls – she managed to get her mother onto the IKEM's transplant programme in Prague. There was no need to wait for a donor, as the daughter offered her mother her own kidney.

Before the transplant, the mother had an operation on her calcified heart valves and the condition of her thin bones improved a little. Everything turned out well. Half a year later came the transplant. Indeed it is impossible to tell that either Mrs Ružena has only one functioning kidney. In the room of the Brussels Martin's Hotel we heard a similar story from Andre Bek and his partner and donor Jose Rutten. This time too the story was one of a love that dwelled in the kidney.

For more on this subject go to www.transplantace.eu, www.hledamzdravi.cz (there is an article and a brochure entitled "Love Dwells in the Kidney"), www.ikem.cz (chapter on "*Transplantcentrum*"), and in

English ec.europa.eu/health/blood_tissues_organ, containing information on European activities in this field of medicine.

Photo caption: For those on the waiting list for a donor organ, walking the dog is often an unfulfilled dream.

Photo caption: Skating, another everyday miracle, and one that patients can enjoy after a transplant.

Photo caption: Dialysis helps people with kidneys that do not work properly, but transplants are usually a far better solution for them for years to come.

Photo credit: Foto Profimedia.cz

Photo caption: Many of those affected return from their operation to regular sport.

Photo caption: The time during which the donated organ is outside the body's circulation should be kept to a minimum.

Photo credit: Foto Profimedia.cz