

Open Letter about the Dark Side of Organ Donation

Currently one topic is again much heard of: Organ donation. Health insurances are sending us informative material and donation passes, schools are busy promoting it and all kinds of celebrities are calling our attention to it via more or less witty ads.

What about this hype?

First of all this is driven by the new German law on organ donation which became effective in autumn 2012. According to our politicians people in this country shall consider donating their organs. However, there is no obligation to make up your mind or fill in the donation pass.

But why is this all being discussed just now?

The reason for all these activities being, of course, to again increase our willingness to donate organs which suffered considerably due to the recent hospital scandals. And there seems to be a lot of money available: Millions of nice colourful brochures and funny tv-ads are meant to lure us to donating our organs for a needing person. One even has a bad conscience when intending to keep your organs to oneself after death!

After death ... Here the trouble begins. Because you are in fact not dead the moment the organs are taken from you. Did you know that? All you are is dead by definition which makes all the difference.

So here is the main object of this open letter. Until this day we are lacking an information campaign which really deserves the name. Such campaign would have to be unbiased and illuminate the pros and cons, chances and risks, but exactly this does not happen. Instead we are informed extremely one-sidedly. All we get is the view of the people desperately waiting for an organ. Where is talk about the donors? At least it is them who first have to die before any organ can be transplanted. It is, therefore, the donors which I am primarily concerned with. Everybody who has filled in a donor card can become a potential donor. So before you do that it is important that you know the WHOLE truth about it and not just parts. Only fully-informed you can make a secure decision for yourself and your loved ones. This open letter is aimed to give you any missing information and on top of that – I promise you will be surprised!

First let me introduce myself shortly so you know who you are dealing with: I worked a very long time in intensive care so I am strongly connected to the topics brain death and organ donation. In this world between life and death, human being and machine, I have seen a lot, including so-called “brain-deads”. Later I was active in transplant surgery and know, therefore, what some people go through with their new organ and which phenomena can occur when “harvesting” organs. The problem of brain death has been a central theme all my life. And it is, unfortunately, the main point in organ transplantation as this sector of medicine would otherwise not exist at all.

I'll now tell you something about brain death and its background, but also about my experiences with brain-dead patients. I'm sure there are certain things you have not imagined. But first things first.

We deal with a lot of problems every day, but illness, death and dying we displace. Yet these issues remain important for us, because they will catch us all. We think we know all about death. It's perfectly clear what death is ... or? But what is it actually?

The death of a person is a very intractable and not quite limitable process. Previously, it was a complex phenomenon and had medical, theological, philosophical and legal aspects. Now it's basically just a medical phenomenon. In Germany there is no longer a legal definition of death. But there is another: In medicine it is described as "irreversible loss of function of the respiratory, circulatory and central nervous system. We make a distinction between clinical and biological death. Clinical death is characterized by complete circulatory arrest and uncertain signs of death. Only the certain signs of death (dead spots, rigor mortis, self-

dissolution) indicate the biological death which is immediately followed by the disintegration of the body. Between the clinical and biological death there is a period during which a reanimation may still be successful. The actual death can be both a momentary event but also the period of time between the detection of uncertain death syndromes until the appearance of the certain ones. Biochemically, death is not a single event but rather a process. My experience has taught me that sometimes many hours can pass between the occurrence of uncertain and certain death signs. During this period even certain body reactions may eventually be caused. Incidental are the infamous seemingly dead which is the reason for so many cultures to guard their dead for three days. We know nothing about the condition of the patient hovering between life and death. Nevertheless people at this stage are today declared dead.

This brings us to the central nucleus of the hidden truths: The fundamental problem of transplant medicine is, in fact, that you cannot use organs of a dead man! They cannot be brought back to life just as little as the dead body itself. So functioning organs can only be taken from a living human being. Yes, you read correctly. These people are alive when their organs are "harvested". They are killed only then.

"I do not believe this. That can not be!" I hear some of you say. On the organ donor card this reads completely different! It says: "In the event that after my death a donation of organs / tissues for transplantation purposes comes into question"?

Here is the brain death comes into play. With it the impossible can be achieved. The notion of brain death and its definition only exist since 1968. It has a story of its own and begins with a report which was then created at Harvard Medical School, Boston / USA. At that time there were two acute problems which had to be solved. For one, medical science finally was able to transplant organs. Professor Christiaan Barnard had performed its first heart transplant which made him world famous. What few people knew at the time: With this operation he had defied all standards applicable at that time and was even threatened with a charge of murder. By the way, a heart surgeon was prosecuted at the same time in Japan for a similar reason. The Commission in Boston therefore defined brain death as the new death and recommended that it be regarded hitherto as a person's death. Thus, immediately there were more organs which could be "harvested" ...

Until today the assumption holds that the new definition of death was made for exactly that reason. Secondly: In 1968 there was another problem which fitted very well: Intensive therapy which was still relatively young but rapidly developing left more and more patients in an intermediate state between life and death. These people sometimes vegetated for years without consciousness and their supply cost much money. Without intensive therapy, however, they would never have come to this state but would have died much earlier. The opinion also clarified the status of these patients. In the end all preconditions were created. Death had been redefined and brought forward – transplant medicine was born!

Removing organs from the dying, however, was originally being considered only for a transitional period, namely just until medical technology would be able to produce functioning organ replacements. By the way: The 1968 definition of brain death still included the loss of all reflexes, i. e. the brain dead at that time were not able to move or react with any reflexes whatsoever. But that changed slowly over the years. Today, a patient is also deemed brain dead when he moves his arms and legs and makes sounds. I ask you: Does this look like a dead man?

How is brain death now exactly defined by science?

First of all, an international uniform definition for the diagnosis of brain death does not exist. Each country has its own and, consequently, that also means that the patient is (brain) dead in one country and not in the next! Absurd. Important for you in this regard: When on holiday or

travelling abroad it is always the organ donation scheme of the country in which you currently are that applies! Therefore you should inform yourself.

The German Medical Association (incidentally not a real chamber but an unregistered association without legal capacity which actually represents the medical profession politically) defined brain death as a state of irreversible extinction of the overall function of the cerebrum, cerebellum and brain stem. At the same time, the heart and circulatory functions are maintained artificially by controlled ventilation. In case the machines are switched off the patient should, therefore, die very quickly. That's the rule of which there are some exceptions, however ...

How is brain death determined?

The diagnosis of brain death is achieved by physical examinations. These are usually supplemented by apparatus tests which, however, are not obligatory. Determining brain death is painful because a reaction of the patient is provoked by pain stimuli such as pinching, stabbing, suffocation and ice water rinses. And it is even carried out four times, twice at an interval of 12 or 72 hours, depending on the type of brain injury. The depth of unconsciousness, respiratory arrest and the reflexes assigned to the brain stem are being examined by two independent physicians who need to have several years of experience with brain-damaged patients. Both doctors must not be involved in neither the removal of organs nor the transplant. But this seems to be handled rather laxly as they may well cooperate with the German Foundation for Organ Transplantation (DSO). DSO is actually supportive in choosing these doctors – honni soit qui mal y pense ...

Perhaps you will now say: "In the end it does not matter what's happening, I won't be feeling anything anyway!" Are you sure? Just this is very questionable. Even if an EEG was written and is showing a zero line, that does not necessarily mean that the patient is without consciousness. We just think this is the case, but we do not know for sure. Why? Because science can not prove or measure awareness which means that we can not recognize the moment when the consciousness dies or leaves the body! Sometimes "brain dead" show certain signs which suggest that in fact they do take notice of quite a bit of what you do to them: Defensive movements, reactions such as increasing blood pressure and pulse rise or sweating, skin rashes etc. can be perceived. Or the visible flexing of individual muscles or muscle groups when you tell them that you are going to turn them over or do whatever. All of this takes place. Not with each and every patient, of course – some really do not react at all. But still I would be careful not to say they do not feel anything ... Perhaps they simply can not make themselves noticeable? I myself have experienced that sometimes patients gave hints of great stress when being visited. These can sometimes even be triggered by the (supposedly) loving wife whose presence renders the body tense as a bow, whereas the mother makes it calm and relaxed. You can sometimes see these things look at them and you have to look for them because they are all observable events that besides me were shared also by other people having worked or working in intensive care. Unfortunately, yet there was one problem with such experiences: The patients' reactions were not repeatable and therefore often quickly dismissed as insignificant. For the first time I saw the like in the mid eighties when we had a "brain dead" patient in our unit. When I took care of him in the presence of a student nurse, the patient did something which was in fact both medically and humanly impossible: He slowly raised his arms and put his hands on my shoulders! There they lay for a short time, then they slid slowly down the side again. I was so scared that I screamed out loudly. Had it not been for the student to witness the scene I would not have believed it myself! Later some sort of reflexes were suspected to have been the cause. Now that could definitely not be right because slow and aimed movements of both arms can never be reflexes. At least, due to this event no organs were then taken from him. The patient died a few days later peacefully amongst his family.

But what I had experienced with him kept worrying and bothering me. At that time there was no word for it, but today in the German-speaking area the term "Lazarus phenomenon" is used for such apparent signs of life. According to the definition they are said to be movements which can be triggered either spontaneously or by touching. They are interpreted as reflexes emanating from the spinal cord and officially should have nothing to do with any brain activity. The name of this phenomenon was inspired by St. Lazarus who is said to have risen from the dead. During my many years in intensive care I witnessed it several times.

After having taken care of such people myself I do not believe in brain death nor its definition. I trust my eyes, my hands and my intuition. Brain-dead patients to me are unconscious people very much like other coma patients. If brain death really were to mark the death of a man, then man would be nothing else but his brain. It's important all right. But: Without the body there would not be the brain! If there were no doubts about brain death, there would be no discussion about anesthesia during the removal of organs. In this country it is not deemed necessary. The Swiss, however, made it obligatory. The reason being that there can be defensive movements of brain dead on the surgery table ... If you are scared now: These are no horror stories but (secret) facts which are well known within the relevant circles. Even brain death misdiagnoses are not unheard of: In 2008, there were reports of this by two scientists from the U.S. And the rare but possible defensive movements in the surgery room speak for themselves. Could it not be possible that we are disturbing the dying process by the explanation and torment the patient unnecessarily? Nevertheless, we go on as before just as if these things did not exist. However, doubts are increasing worldwide whether brain death can really be defined as the death of a man. Many reputable scientists look at it as being only a gray zone between life and death but not death itself. The Boston medical ethicist Robert Truog speaks of a "legal fiction that treats individuals as if they were dead, even though they are alive or at least it is not clear whether they are dead." In the U.S. it is meanwhile conceded that the donor is alive and that he only dies by the removal of his organs. "Justified killing" is the term commonly used. However, even formerly enthusiastic supporters of the concept of brain death like the neurologist Alan Shewmon have become strong opponents over the years from their own experiences. Shewmon, who encountered diverse phenomena with his patients, examined many cases of brain dead. He documented 175 patients with long survival times, the longest lasting for 14 years.

Let's summarize the essentials: Brain dead are seriously ill, probably dying. However, they only die on the operating table by the removal of their organs. These are already desperately waited for by multiple recipients which, in turn, are in the terrible situation that their long-term survival depends on the death of another person - sometimes of several people ...

At first, the lucky organ recipient enjoys his new life with the the other organ but overtime it is not that easy; He has to take a lot of rather strong drugs with possible unwanted side effects. The immunosuppressive drugs weaken the body's immune system that would otherwise attack the foreign organ. Since they have severe side effects, other medications are needed. Because the normal body defence against infections and cancer is also reduced by these drugs, there are many infections and the risk of cancer is increased by a multiple. In the long run, the amount of drugs may also damage the liver or kidney, which can make further organ transplants necessary. People with two or three transplants are not rare; in fact there were even patients with seven foreign organs.

Living with somebody else's organ is not easy for some people. They often have a strange relationship with it: Some give it a name and talk to it. Some simply cannot accept it as their own although they really want to. Some struggle with the feeling of having caused the death of another person. Many would like to know who it was whose organ they now carry within themselves. After all, the day they got it was the day the other person died. This idea often torments them. At the same time they and their families are very grateful to the organ donor! And then there are also patients who change with the new organ. Some eat differently or

change their behaviour. One often gets the impression as if the other person or his traits break through. In spite of the transplantation most organ recipients are not able to return to a normal life.

At this point, one always gets to hear: "But if they do not get new organs these poor people have to die!" That may well be. It has to be clear: There is always one death involved, either the donor or the recipient. I know that sounds tough. But such is life ... By the way: It is often forgotten that one can also die easily from the complications of a transplantation. Such possible complications are rejections, side effects of the therapy, infections, bleedings, organ failure or tumors.

Is this what you imagined? Probably not.

There is always talk that we have to increase the number of donors by all means. In fact, the donation of one's organs is almost expected these days! It is then always emphasized that people on the waiting list have to die because there are not enough donors. That's not true. These people die of their genuine illness such as other patients with heart disease or cancer! Speaking of donations: A donation means that something is given away voluntarily, it is an act of brotherhood. To donate one's own organs, without which one dies, should, therefore, never be expected of anybody!

Whoever gives his consent to the removal of his organs, must know that he will have a different death than usual: It will not be peaceful and quiet together with his family, not even in a bed, but in the technical and sterile atmosphere of an operating room in the middle of several medical teams. Whether there will be the feeling of pain, no one knows. In any case, we suppose analgesia, but this is not proven. Due to occasional signs to the contrary it is advisable to require a general narcosis. This can be done on the organ donor card. This brings me back again to the donation card. Important to know: You may fill it in, but you don't have to. I would still recommend filling it in so that in the event one's family is relieved and not burdened with this difficult decision in a dramatic situation. By the way: Even minors may declare their willingness to donate organs and tissues from the age of 16 and their objection from the age of 14. Parental consent is not necessary. As you can imagine, this can turn out dangerous. Are you really, at this early age, in a position to assess the consequences of such a decision alone?

Do you know what the expression "donation of organs and tissues" really means? Do you know, for example,

1. which organs are removed? Nowadays this can be whole parts of the body and limbs, but especially the lungs, heart, kidneys, liver, small intestine and pancreas.
2. what is meant by "tissues"? These are skin, bones and bone parts, heart valves, eyes, cartilage, tendons and ligaments. The skin is removed, the large bones taken.
3. that processed transplants are authorized as medicinal products and become tradable?
4. that also the cosmetic industry uses these processed tissues?
5. that man has become the raw material of our century? Tissues can also be taken from deceased. The value of a human corpse in the U.S.: \$ 250,000!

I think, all of you have to come to grips with this, right?

Nearly 82 million people in Germany are being put under moral pressure by the DSO, associations, organizations and politicians to donate organs for 12,000 potential recipients (a number in fact unchanged for years!). What a disproportion! In the old days, potential donors could and should be reported by their doctors to the DSO. This was probably done by too few doctors, so the system was changed and special transplant agents installed in the hospitals. These people scan intensive care units once a day looking for potential donors. In case they find someone who is eligible the machinery gets started - and it is fast and effective. In its annual report for 2012 the DSO writes that 70% of the "donation processes" as they call the

harvesting of organs were performed within 18 hours, more than a quarter within 12 hours. So many (or rather: so few!) hours were left to the next of kin to think about the “donation process” after brain death was detected. In case they reject the idea of organ donation, then the machines are turned off. If they object to this kind of killing because there is still some hope it may well happen that the health insurance no longer covers the cost after brain death was diagnosed. The patient is considered dead and the insurance does not pay for a dead person. The family may then end up having to carry all the costs. On the other hand, if the family consents, then the "donor conditioning" begins – and sometimes even earlier. These are tests and measures that you would rather spare a dying patient and which only aim at the preparation of the donor organs. And then the explantation takes place ...

This is organ donation today in Germany. So now you know. However, none of the things I mentioned are secret. They are not! The internet and the media are full of it ... It is just that one first has to have a reason to look for it!

I think we need to go different ways than up to now.

First of all, everything must be done to prevent organs from failing at all, incidentally also by ourselves, because besides hepatitis viruses also alcohol, drug abuse or other poisonings can lead to liver failure. The causes of kidney failure are more complex: Chronic inflammations, diabetes and high blood pressure, but also congenital kidney malformations and painkiller abuse can cause kidney failure. You see, some of the reasons may in fact be influenced by ourselves !

And then we should remember that medical transplantation was originally intended as a temporary solution. I have the strong feeling that we could have found other means of organ replacement long ago had all forces really been focused in this direction. We can fly to the moon, are connected with each other worldwide by the internet and should not be in a position to compensate organ functions? It is probably easier to make use of the dying ... Their explantation should be substituted as soon as possible by artificial organ replacement. Furthermore, already today human organs can be grown from certain stem cells and xenotransplants are within reach, i. e. organ transplants from animals to humans. I myself put great hopes in the future of new technologies and strongly wish that the explantation of people will soon be a thing of the past.

Death is more than the death of an organ. Brain death means that the whole body is alive, only the damaged brain no longer works. I do not deny that almost all brain dead die and can understand those who say that they do not want to languish forever unconscious. But this can be avoided also differently: Whoever fears long sufferings may adopt a living will. This can contain all questions of treatment or their renouncing. I decide for myself what shall happen to me in certain critical situations of life. I also determine the conditions under which the treatment should be discontinued. Sample wordings for such a “Patientenverfügung” can be found here: <http://www.dnoti.de/DOC/2004/Formulierung.pdf>. However, it is always advisable to also appoint a person who ensures that this will is actually observed. I for one would like to die with the help of medication as undisturbed as possible.

I myself reject the idea of organ donation. This implies, of course, that I do not want an organ of another person. I would not be able to accept it anyway and certainly reject it. However, I would not rule out a living donation for me. So I would give one of my kidneys to my husband or my sister and also accept one from them.

I think that we humans are neither divisible nor consisting of several single parts. This is not what nature has provided for; otherwise such a mechanistic understanding would allow us to take all organs from anywhere and install them again somewhere else. Then there would not be any rejections by which the body tries to get rid again of the new organ. But these reactions are normal. It seems we are more than just the sum of our parts

Now you know what's going on. I have deliberately omitted internet links except one. Look for the topics that you need. The internet is full of them. Think again in quiet about the pros and cons and then decide If you want to make your body available as an organ donor, then go ahead, I salute you! But please do not forget to request a general anaesthesia during the removal of the organs.

In dealing with these issues one should perhaps again be aware that you should live every single day of your life in such a way that nothing material is left out or to be regretted. This then lets you go in quiet when it is time. I wish you from my heart that you never have to think about these issues again after filling out the card.

Health and a long life!

Drive carefully ...

Andrea v. Wilmowsky

P.S.: This open letter may be redistributed and shared. I only ask to bear this in mind: My intention is to inform, not to indoctrinate. Thanks for your understanding!