



Become an
ORGAN
SPONSOR

Answers to

Important Questions.

BZgA

Bundeszentrale
für
gesundheitliche
Aufklärung

**Organ Donation**
give life.

A portrait of a man with short brown hair, wearing black-rimmed glasses and a blue t-shirt. He is looking directly at the camera with a slight smile. The background is a dark, neutral grey.

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> GET THE FACTS

> REACH A PERSONAL DECISION

> COMPLETE THE ORGAN DONOR CARD

GET A CLEAR PICTURE

Questions relating to life and death are never easy. The same is true when it comes to organ and tissue donation. But only if you decide for yourself can you exercise your right of self-determination and possibly relieve your next of kin of a great burden.



There is no »Right« or »Wrong« when it comes to the question of deciding for or against organ and tissue donation. You can only find your own, personal answer to this question, and no one has the right to criticise your decision.

It is important that you arrive at a decision yourself, document it on an organ donor card, and talk about it with relatives or other persons close to you.

This brochure is designed to help you make a decision. It gives answers to important questions relating to organ and tissue donation – so you can get a clear picture.



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WHAT IS ORGAN TRANSPLANTATION?

The organ transplantation procedure involves the transfer of **functioning organs** or tissues of a deceased person to a severely ill or impaired person. The aim of operations of this kind is to restore the lost function of the recipient's own organs or tissues with the help of the transplanted organs or tissues. The following organs, in particular, can currently be transplanted: heart, lung, liver, kidney, pancreas and intestine. They come from medically suitable deceased persons, whose death has been ascertained by two, independent doctors and who have previously given their consent to removal of their organs. The blood circulation in the body of the deceased person is maintained until the time of organ removal. Living donation of a kidney, or part of the liver or other organs, may be open to consideration under certain circumstances (see Question 27: Can you already donate organs during your lifetime?). The tissues that can be transplanted include the cornea of the eye. It can still be removed several hours after the death of a deceased donor.

HOW SUCCESSFULLY CAN ORGANS BE TRANSPLANTED?

Thanks to the extensive progress achieved in medicine, the success rates for all transplantable organs have steadily increased and are today very high. In this respect, there is a difference between the rates following transplantation of the organs of deceased or living donors. In the case of kidneys, up to 85 or 93 percent of the transplanted organs, respectively, are still functional after one year; up to 71 or 85 percent of donated kidneys are still working after five years. The success rates for heart, liver, lung and pancreas transplants are only marginally lower.

HOW GREAT IS THE DEMAND FOR TRANSPLANTS?

The same applies to all transplantable organs: the demand exceeds the number of donated organs. For example, only 2,144 kidneys were transplanted in 2009. In contrast, there were roughly 8,000 patients on the waiting list for a kidney transplant in 2009. Consequently, the waiting time for a kidney donated post mortem averages between five and six years. 347 hearts were transplanted in Germany in 2009, although that figure only corresponded to

roughly one-third of the number of patients who were urgently waiting for a donated heart. The demand for liver transplants is likewise greater than the number of organs transplanted: 1,800 new patients were registered for a liver transplant in 2009, while 1,119 liver transplantations were actually performed.



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WHAT DOES THE TRANSPLANTATION ACT SAY?

The German Transplantation Act was adopted by the Bundestag and Bundesrat by broad consensus in 1997 and amended in 2007. It regulates the donation, removal and transplantation of organs and tissues. In practice, the statutory provisions hardly constitute any change in content compared to the legal practice that has existed for some 30 years and the Code of Practice of the German transplantation centres, but they put this practice on a sound legal footing.

The core elements of the Act are as follows:

- > The transplantation of vital organs, such as hearts, lungs, livers, kidneys or intestines, may only be performed at transplantation centres licensed to do so.
- > The fields of removal, allocation and transplantation must be separated from each other in terms of organisation and personnel.
- > Except in the case of living donation, organs and tissues may not be removed until the death of the organ donor has been ascertained. The total brain death of the organ donor must also always be ascertained in this context.
- > Death must be ascertained by two experienced doctors, independently of each other, and the result of their examinations must be documented in writing.

- > Everyone should document their decision regarding the question of organ and tissue donation during their lifetime, preferably in writing (organ donor card). If, at the time of death, donation is open to consideration from the medical point of view, the relatives are asked whether the deceased had expressed his or her wishes regarding organ and tissue donation during his or her lifetime, in writing or verbally. If the relatives are not aware of any such wishes, they are asked what they think the deceased would probably have wanted, and requested to make a decision in his or her spirit.
- > The transplantation centres are required to keep waiting lists for the transplantation of organs subject to allocation. In this respect, inclusion in the waiting list and the allocation of donated organs must be handled in accordance with rules that reflect the latest state of the art in medical science. Donated organs must be allocated to suitable patients in accordance with these rules throughout Germany.
- > Living donation of a non-regenerable organ is only possible for the benefit of a relative of the first or second degree, the spouse, the civil partner, the fiancé(e) or another person particularly close to the donor.
- > Organ trading and the active or passive transplantation of traded organs are acts punishable by law.



WHY ARE THERE LONG WAITING LISTS?

Since far fewer organs are donated than required (see Question 3: How great is the demand for transplants?), there is a need to allocate the available donated organs as fairly as possible. The Transplantation Act therefore imperatively prescribes that both inclusion in the single waiting list by the transplantation centres and organ distribution by an allocation agency must be handled in accordance with medically based rules, particularly according to necessity, prospects of success and urgency. This leads to the personal »ranking« on the waiting list, which is regularly checked for medically relevant changes in the transplantation prerequisites during the waiting time. The length of the waiting lists for kidney transplants is also partly due to the fact that exemplary, high-quality dialysis treatment is available in Germany, meaning that patients with chronic renal failure can live with their illness for many years. There is, however, no doubt in this context that a kidney transplant is usually the medically best form of treatment for these people.

WHAT IS BRAIN DEATH AND HOW IS IT ASCERTAINED?

Brain death is defined as the definitive, irreversible failure of the overall function of cerebrum, cerebellum and brain stem (total brain death). When all brain functions fail, a person ceases to be a living being as a physical and mental entity. When the integrative control functions of the brain are lost, the »human system« breaks down. Every possibility of conscious perception, including the sensation of pain, the capacity to think, etc., is irretrievably lost, and the possibility of regaining consciousness is completely ruled out. The brain is disconnected from the blood flow, and its cells decay, even if blood circulation in the rest of the body is maintained artificially. In the case of brain-dead persons who themselves, or whose relatives, have previously consented to organ and tissue removal, the doctors attempt to preserve the functional capacity of the organs to be transplanted by initiating artificial respiration and maintaining the cardiac function using the means of intensive medicine until the time of removal. According to the Transplantation Act, brain death has to be diagnosed by two experienced doctors, independently of each other.



The procedure for this clinical and apparatus-based examination is exactly prescribed in the Guidelines of the German Medical Association on the basis of the latest state of the art in medical science.

The aim of these examinations is to establish beyond doubt the irrevocable failure of the complete brain, and thus its loss of function, as a scientific-medical criterion for the occurrence of the death of a human being.

DOES ORGAN TRADING EXIST IN GERMANY?

The Transplantation Act makes organ trading punishable by law. Also liable to punishment are persons who remove, transplant, or have transplanted as the recipient, organs obtained through forbidden trading. The German transplantation centres had already clearly rejected every form of commercialisation of organ donation and transplantation in their Code of Practice of 1987.

HOW ARE ORGAN DONATION AND TRANSPLANTATION ORGANISED AND FINANCED IN GERMANY?

If it is clear, following the diagnosis of brain death, that there is a person who has died of brain death in the intensive-care unit of a hospital, and the doctors are of the opinion that this person may possibly be open to consideration as an organ or tissue donor, the doctors notify the nearest Organisation Centre of the Deutsche Stiftung Organtransplantation (German Foundation for Organ Transplantation – DSO). If consent has been given to donation – either in the form of an organ donor card, or by indication of the will of the deceased by his or her relatives – the Organisation Centre occasions the necessary laboratory tests and medical examinations. Preparations are then made for organ and tissue removal, and Eurotransplant, the international allocation agency, is informed.

Eurotransplant is a non-profit foundation and responsible for the allocation of removed organs in accordance with the medically based Guidelines of the German Medical Association. Once a suitable recipient has been found, the removed and preserved organs are transported to the relevant transplantation centre for transplantation. The DSO refunds the personnel and material costs arising in connection with an organ and tissue donation – it pays for the examinations and for transport of the donated organs to the transplantation

centres. The corresponding budget is made available to the DSO by the National Association of Statutory Health Insurance Funds. The costs for transplantation of the donated organ are borne by the recipient's health insurance.

DO YOU HAVE TO UNDERGO A MEDICAL EXAMINATION IF YOU DECIDE IN FAVOUR OF ORGAN AND TISSUE DONATION?

No. An examination is unnecessary if a person chooses to donate organs and tissues at the time of death, e.g. by completing an organ donor card. Nor would it make sense at this time.

9.

WHAT ORGANS AND TISSUES CAN YOU DONATE?

10

The following organs and tissues can currently be donated and transplanted after death: heart, lungs, liver, kidneys, pancreas, intestine and parts of the skin (organs), as well as the cornea of the eye, heart valves and parts of the blood vessels, the cerebral membrane, the bony tissue, the cartilaginous tissue and the tendons (tissues).

CAN ORGANS AND TISSUES ONLY BE TRANSPLANTED IN UNCHANGED FORM?

Organs are generally transplanted whole, in unchanged form.

If transplantation is impossible for medical reasons, owing to the condition of a donated organ, individual parts, such as the heart valves, may also be removed and transplanted where appropriate. In addition, medical progress enables the use of highly complex technical procedures to manufacture medicinal preparations from human tissue that are important for the treatment of various illnesses.

12.

UP TO WHAT AGE CAN YOU DONATE ORGANS AND TISSUES?

There is no fixed age limit for organ and tissue donation. A medical assessment at the time of death is necessary to determine whether or not donated organs and tissues are suitable for transplantation.

The important aspect in this context is not the actual age of the donor, but his or her state of health, i.e. the biological age of the organs and tissues. Generally speaking, the younger the deceased person, the more organs are suitable for transplantation. However, even the fully functional kidney of a person who dies at the age of 70 or more can allow someone else to live an almost normal life again. Similarly, there is no fixed age limit for such tissues as ossicles (the bones of the middle ear) and corneas.

IS THE IDENTITY OF THE DONOR REVEALED TO THE RECIPIENT?

No, the name of the donor is not disclosed to the recipient. Conversely, the relatives of the donor are likewise not informed of who received a donated organ. This anonymity prevents the development of reciprocal dependences, which would be a strain on all concerned. On request, however, the transplantation centre does inform the relatives of whether the organ or organs was or were transplanted successfully.

13.

IS THERE ANY FINANCIAL COMPENSATION FOR ORGAN AND TISSUE DONATION?

14.

No. The Transplantation Act imperatively prescribes that willingness to donate organs and tissues may not be dependent on financial considerations. It is to be based exclusively on a voluntary, humanitarian decision. This is the reason why, for example, the costs for the funeral of a donor are likewise not paid for.

On the other hand, the health insurance funds or other funding agencies bear all costs incurred in connection with post-mortem organ removal and organ transplantation. The assumption of costs resulting from a living donation should be clarified with the health insurance fund and the transplantation centre in writing in advance.

WHO BEARS THE COSTS FOR ORGAN TRANSPLANTATION?

The costs for the removal of organs from deceased persons are refunded to the hospitals by the Deutsche Stiftung Organtransplantation (German Foundation for Organ Transplantation – DSO) on the basis of fixed flat rates. These flat rates are agreed upon between the National Association of Statutory Health Insurance Funds, the German Hospital Federation, the German Medical Association and the DSO, and are made available to the DSO by the health insurance funds. In cases of living donation, the necessary preliminary examinations and organ removal are paid for by the health insurance fund of the recipient of the transplant. A flat-rate remuneration is also paid for the actual organ transplantation. These costs are likewise borne by the health insurance fund of the organ recipient.

ARE DONATED ORGANS USED FOR SCIENTIFIC PURPOSES?

No, donated organs do not serve scientific purposes. The sole purpose of donated organs is to provide sick persons with optimum medical treatment. If anyone wants to put their body at the disposal of science following their death, they should contact the Anatomical Institute of a university hospital.

16.

DO YOU NEED TO DOCUMENT YOUR INTENTION TO DONATE ORGANS AND TISSUES IN A WILL?

No. Declaring your willingness to donate organs and tissues in a will would be pointless, since a will is opened at a time when it is too late for organ removal.

17.

SHOULD YOU HAVE YOUR ORGAN DONOR CARD WITH YOU AT ALL TIMES?

18.

Yes. It makes sense to carry it with your driving licence or ID card. If you don't have it with you at all times, you should inform your relatives of your decision regarding organ and tissue donation and tell them that you have an organ donor card. Needless to say, you can also inform a trusted person who is not a relative, or ask him or her to keep your organ donor card.

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DO MINORS NEED THE SIGNATURE OF A PERSON HAVING PARENTAL POWER?

No. Under the Transplantation Act, the consent of a person having parental power is not required if a minor over the age of 16 wishes to declare his or her willingness to donate organs and tissues, or a minor over the age of 14 wishes to express his or her opposition to donation.

CAN YOU REVOKE YOUR CONSENT TO ORGAN AND TISSUE DONATION?

Yes, at any time. If you want to revoke or change your decision, you need only tear up the organ donor card. The changed decision, whatever it may be, should be documented in a new organ donor card. Moreover, it makes sense to inform your relatives or some other trusted person that you have changed your decision.

20

CAN YOU SPECIFY WHO IS TO RECEIVE AN ORGAN DONATED AFTER DEATH?

No. In the case of post-mortem organ donation, you can neither specify the recipient, nor can you exclude certain persons. The persons who receive donated organs are determined solely in accordance with medically based rules, particularly according to the prospects of success and urgency.

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CAN YOU SEE THE DECEASED PERSON AGAIN FOLLOWING ORGAN AND TISSUE REMOVAL?

Yes. Following removal, the relatives can take their leave of the deceased person in any way they wish. In this context, they can, for example, see that the operation wound has been closed – as in a living person. The body is handed over for the funeral in a dignified state.

22.



WHERE ARE THE ORGANS AND TISSUES REMOVED?

23.

The organs and tissues are removed in an operating theatre, taking the same surgical care as in any other operation.



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24.

CAN YOU RESTRICT YOUR WILLINGNESS TO DONATE TO CERTAIN ORGANS?

Yes, and without stating reasons. On the organ donor card, you can exclude certain organs or tissues from removal, or restrict removal to certain organs and tissues only, by marking the corresponding field on the organ donor card and entering the appropriate text, where necessary. It naturally makes sense to also talk about this restricted willingness to donate with relatives or some other trusted person.

25.

WHERE CAN YOU GET AN ORGAN DONOR CARD?

Organ donor cards can be requested from the **Federal Centre for Health Education (BZgA)** and the **Deutsche Stiftung Organtransplantation (German Foundation for Organ Transplantation – DSO)**. The statutory health insurance funds and the private health insurers provide their insureds with organ donor cards. The cards are likewise available from many pharmacies, hospitals, registration offices and doctors' surgeries. In addition, the organ donor card can also be downloaded from the Internet offering of the BZgA at www.organspende-info.de.

The organ donor card is free of charge and in no way involves a request for a financial donation. You can also document your decision informally on a signed sheet of paper. All previous »Declarations on Organ Donation« naturally remain valid. The organ donation card is equally valid abroad.

WHAT IS THE POSITION OF THE CHURCHES REGARDING ORGAN DONATION?

The (Roman Catholic) German Bishops' Conference and the Council of the Evangelical Church in Germany published a joint declaration on organ transplantation in 1990. Since that time, discussions on the subject, particularly on the question of death, have taken place at all levels in both churches (in parallel with the debates on the draft for an Organ Transplantation Act). A definitive answer to the question has still not been reached, and is currently not to be expected. Nevertheless, both churches welcomed the adoption of the Transplantation Act in 1997, again emphasising that organ and tissue donation can be an act of charity. Among other things, the joint declaration of 1990 includes the following statements: »According to the Christian view, life, and thus the body, is a gift of the Creator that man cannot dispose of at will, but that he may use out of charity after carefully examining his conscience.«

26.

»Anyone who gives their consent to the removal of organs following their own death, is acting in an ethically responsible manner, because this can help other people whose life is subject to extreme burdens or threats. Relatives who consent to organ transplantation are not guilty of a lack of piety towards the deceased. They are acting in an ethically responsible manner because, despite the pain they feel, they decide in the spirit of the deceased to help other people and save lives by donating organs.«

»The expectation of resurrection of the dead and eternal life is not dependent on the integrity of the corpse. Rather, our belief trusts in our merciful God restoring to life from death.«

»From the Christian point of view, the willingness to donate organs after death is a sign of charity and solidarity with the sick and disabled.«

CAN YOU ALREADY DONATE ORGANS DURING YOUR LIFETIME?

Yes, although the Transplantation Act deliberately imposes substantial restrictions. The kidney is the organ most commonly open to consideration for a living donation. The body has two of these organs, and it is perfectly possible – given healthy kidneys and a generally good state of health – to remove one kidney from a donor without impairing his or her renal function. Under the Act, the living donation of organs that cannot regenerate is permissible only between relatives of the first or second degree (e.g. parents or siblings of the recipient), spouses, civil partners and fiancés, or for the benefit of other persons who have particularly close, personal ties with the donor. For a few years now, there has also been the possibility of children with extremely severe liver damage receiving part of the liver of a parent. Under favourable conditions, this part grows in the child's body, developing into a fully functional liver, while the parent's

liver can compensate for the loss of the donated part by regrowing. In rare cases, living donation of part of the lung or the pancreas is also possible, but the donated part does not regrow.

Opting to make a living donation is, of course, a particularly hard decision to take. Even though, for example, the donor of a kidney does not generally have to make any direct sacrifices in terms of health – apart from the operation itself – he or she is from then on dependent on the lifelong functioning of what is then his or her only kidney. When making a decision, relatives or other particularly close persons may only let themselves be guided by their concern for a beloved, very close person. But even then, psychological problems cannot be ruled out, and support is necessary. Financial considerations may play no part at all. In order to prevent any and all abuse, the Act requires that an expert committee examines, prior to organ removal, whether there are justified grounds for suspecting that the donor did not consent voluntarily, or whether the organ is even the object of forbidden trading. The aim of this is to ensure that living donation is exclusively an act of charity and care between particularly close persons.



WHO CAN YOU TALK TO ABOUT THE SUBJECT OF ORGAN DONATION?

Generally speaking, with anyone you would like to discuss the subject with, e.g. the circle of friends or the family, the family doctor or a spiritual advisor. In addition, you can also contact the nearest transplantation centre or the self-help and interest groups of organ transplant recipients, as well as the **Organ Donation Information Hotline on 0800 9040400**, which is operated by the Federal Centre for Health Education (BZgA) in collaboration with the German Foundation for Organ Transplantation (DSO).



INFORMATION

Further information is available from

- > BZgA, Ostmerheimer Straße 220, D-51109 Köln, Germany
Fax: 0221 8992-257
www.organspende-info.de

- > Federal Ministry of Health
www.bmg.bund.de

WITH AN ORGAN DONOR CARD,
YOU CAN CLEARLY EXPRESS
YOUR WISHES AND POSSIBLY
RELIEVE YOUR RELATIVES OF
A GREAT BURDEN.

IT IS IMPORTANT TO TALK TO
YOUR NEXT OF KIN ABOUT YOUR
PERSONAL DECISION, SO THAT
THEY ARE AWARE OF IT.

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Anyone can use the detachable organ donor card alongside to document their declaration regarding organ and tissue donation in the event of death. You can consent to the unrestricted donation of organs or tissues, restrict donation, i.e. exclude certain organs and tissues from donation or donate only certain organs and tissues, or object to donation. If you do not want to make the decision yourself, or not immediately, you can assign it to another person, such as your husband/wife, a good friend or some other trusted person.

To make your intentions unmistakably clear, you should mark only one of the five different declarations and add any text that may be necessary. The »Remarks / Special Notes« line can be used, for example, to draw attention to an illness that may be of importance in connection with donation, or to give the name of a person to be notified in the event of your death. Kindly fill in the organ donation card legibly. It makes sense to carry it with your identity papers.

DONOR

Organ Donation Form



according to section 2 of transplant law

Organ Donation

.....
Surname, First name

.....
Date of Birth

.....
Street

.....
Postcode, Town



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In case of questions call the toll-free Hotline Organ donation at 0800/9040400.

WITH AN ORGAN DONOR CARD,
YOU CAN CLEARLY EXPRESS YOUR
WISHES AND POSSIBLY RELIEVE
YOUR RELATIVES OF A GREAT
BURDEN.

ORGAN DONOR CARD

In the case that **organ/tissue donation for transplantation** is possible after my death, I declare:

- YES**, I give permission for organs and tissue to be taken from my body after doctor's certification of death.
- or **YES**, I give permission for the use of organs and tissue with the **exception** of the following:
- or **YES**, I give my permission **only** for the following organs:
- or **NO**, I do not wish organs or tissue to be taken from my body.
- or The following person should decide YES or NO:

.....
Surname, First name

.....
Telephone number

.....
Street

.....
Postcode, Town

.....
Space for **notes/additional information**

.....
DATE

.....
SIGNATURE

KINDLY FILL IN THE
ORGAN DONATION CARD
LEGIBLY AND DETACH IT.



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