



FREQUENTLY ASKED QUESTIONS



European
Reference
Network

Transplantation in Children
(ERN TRANSPLANT-CHILD)



Information for patients:

European Reference Network TransplantChild answers the
most frequently asked questions by patients and families
in the process of transplantation



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1. WHAT IS A TRANSPLANT?

People with irreversible and **permanent damage in one of their organs or tissues** may have no alternative to medical and surgical treatment. In those cases, transplant is the only solution to avoid death or to bring a better quality of life.

A transplant is an operation in which a **healthy organ or tissue from a donor is implanted** into a person or recipient who has an irreversible malfunction of that organ.



The purpose of a transplant is to recover the functions of an organ or tissue, to perpetuate life, to improve quality of life, to reduce the number of hospitalizations and to eliminate the dependence on substitution or support machines.



2. WHAT ARE THE MAIN PROBLEMS WE CAN EXPECT TO APPEAR?

The main problem after transplantation is rejection. The immune cells of our body have an innate response to reject what is not theirs. To avoid rejection it is necessary to give **drugs that reduce such immune response**, that makes us susceptible to infectious diseases and less frequently to some tumours or cancer.

Immunosuppressants use heterogeneous mechanisms of action to suppress the body's immune response. By weakening or reducing your immune system's responses to foreign material, these drugs **reduce your immune system's ability to reject a transplanted organ**.

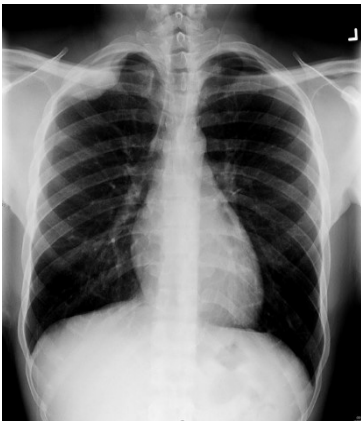


3. WILL I NEED TO TAKE MEDICATION FOR THE REST OF MY LIFE?

Initially, as/since the risk of rejection is greatest, a high level of immunosuppression is required. However, after several months, the organ, the host, or both adapt: the host becomes less responsive while the organ loses its population of donor antigen-presenting donor cells.

Side effects of transplant-specific medication are: decrease of defences, with increased risk of infections and exceptionally, the appearance of tumours. In most cases, these complications are resolved with medical treatment.

4. HOW LONG WILL THE TRANSPLANTED GRAFT LAST?



There has been a **gradual improvement in the overall results** of kidney transplants. Liver transplants can have excellent outcomes. Recipients have been known to live a normal life over 30 years after the operation. Non-compliance with the immunosuppression medical regimen is the first cause of organ failure. **Close follow-up** with your transplant team and primary-care physician can help ensure a good outcome.

Transplant recipients directly contribute to the success of their transplant.

5. HOW IS THE TRANSPLANT PROCEDURE?

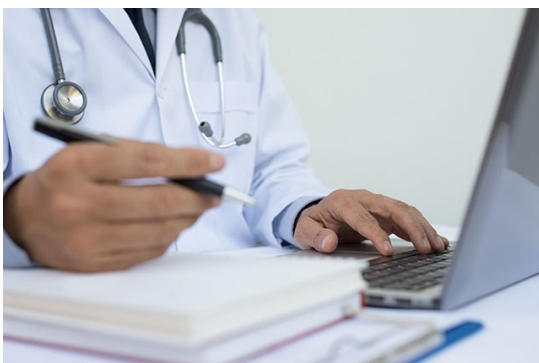
After the positive evaluation by specialists/ your doctors, the child becomes a candidate for transplantation and is included in the so-called waiting list. Then, they have to wait, usually at home, until they receive a call telling them that a suitable organ is available. **The “call” is unexpected and can be in the middle of the night.**

When the family arrives, the child is prepared to go to the operating room and the recipient procedure starts. Finally, the corresponding native organ is removed and the new organ (graft) is implanted.



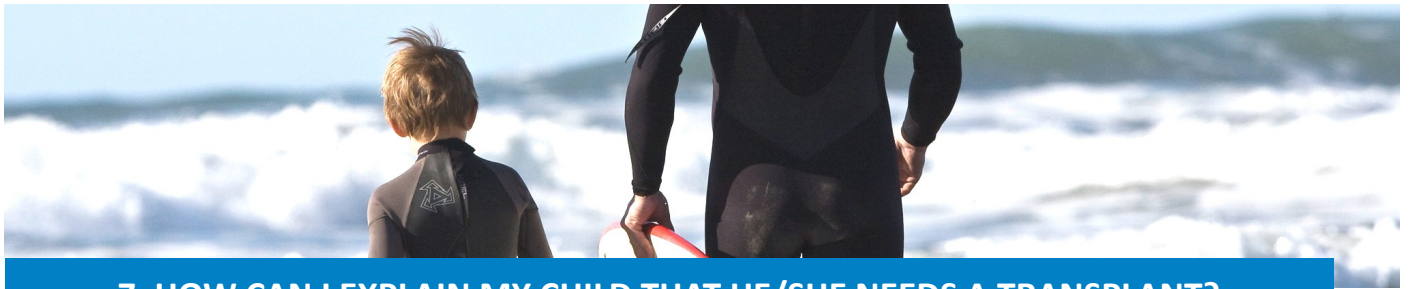
The duration of the procedure depends on the organ and the previous surgical procedures. Generally speaking, an organ transplantation takes from 4 to 8 hours.

6. WHAT ARE THE MAIN RISKS WE FACE IN A TRANSPLANT?



Transplantation is the most complex procedure in the clinical setting. Therefore, the risks are higher than in any other case. Bleeding and intraoperative cardiac arrest are probably the most feared complications.

Bleeding is more common in patients with previous coagulopathy, severe portal hypertension, and re-transplantation. The cause of cardiac arrest is multifactorial, and is related to previous patient's conditions and severe intraoperative bleeding.



7. HOW CAN I EXPLAIN MY CHILD THAT HE/SHE NEEDS A TRANSPLANT?

Your message should be simple, adapted to your child age and previous experience with illness, and they should have the opportunity to ask questions. Children usually understand that some piece of the body (organ) is sick and it needs to be replaced.

Many of them ask about where the organ comes from. We should explain the process of cadaveric donation, and living donations if that is the case, and we should emphasize the generosity and the **positive experience of sharing life**.

Before transplantation, the family will need some visits or even to stay for a while at the hospital. It is important to explain to kids that they will meet many children with similar problems, and to the staff people who will take care of them.

8. EXPECTATIONS

You may expect your child to have a normal life. However, the concept of normal life differs considerably from one to another. Transplanted children can attend school, play sports and spend time with friends. When the quality of life is assessed, **the parents' perception are usually worse than childrens' about their own lives.**



Don't forget to check our Patients and Families portal in **www.transplantchild.eu** where you will find more information on the process of transplantation, the activities of the network and some links for more support.

Please, do not hesitate to contact us if you need further information or if you have any questions or doubts.

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