



Life After a Transplant

Useful tips to take into your new everyday life

Foreword

Dear patient,

Now that you've received a donor organ transplant, a new chapter of your life has begun. You've probably left behind a stressful period of waiting, hoping and anxiety: a time when you may have had to have frequent visits to hospital and had to severely restrict your everyday life. You now have a life ahead of you that you can take control of and actively start shaping for yourself again.

That being said, your new life with the donor organ will also require that you continuously take medication to prevent your body from rejecting it. At the same time, this exposes you to an increased risk of infection. This means that a good and trusting relationship between you, your doctor and your transplant centre is also vitally important in the future. As a patient, there's also a few things you can do to help keep your everyday life as complication-free as possible; these are summarised in this brochure for you in the form of useful everyday tips.

What should I consider in terms of my medication?

How can I protect myself against infections?

What can I do in my free time?

These questions as well as others are answered briefly and in a way that's easy to understand so that you can achieve a good quality of life in a few simple ways.

Please be aware that individual and center related procedures may lead to differing results. This means that not all of the instructions listed here are generally applicable.

We hope that you find great fulfilment in your everyday life and wish you a bright future with your new organ.

Yours sincerely,
Antje Weimann and Anette Bachmann

Publishing Information

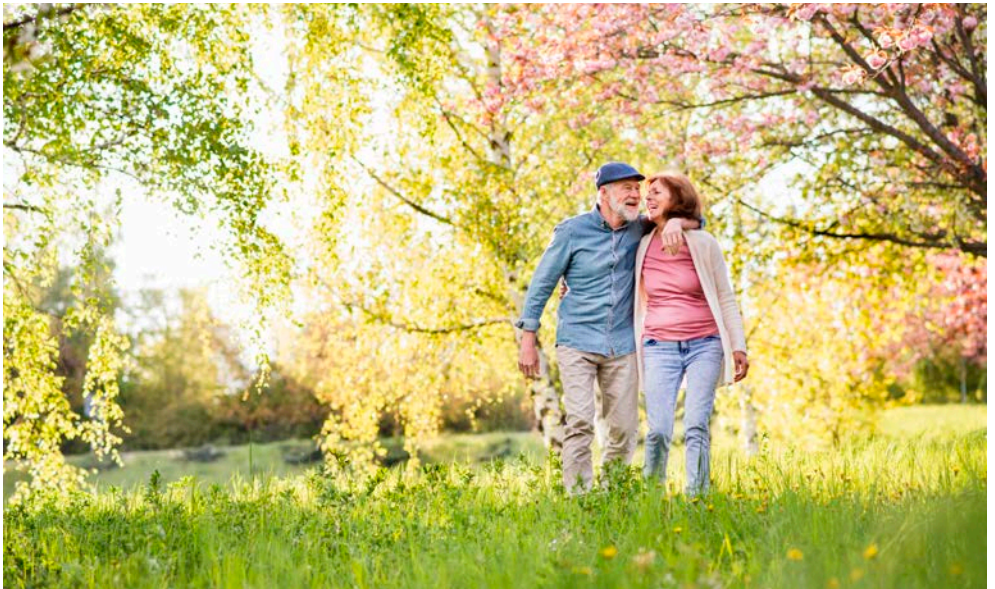
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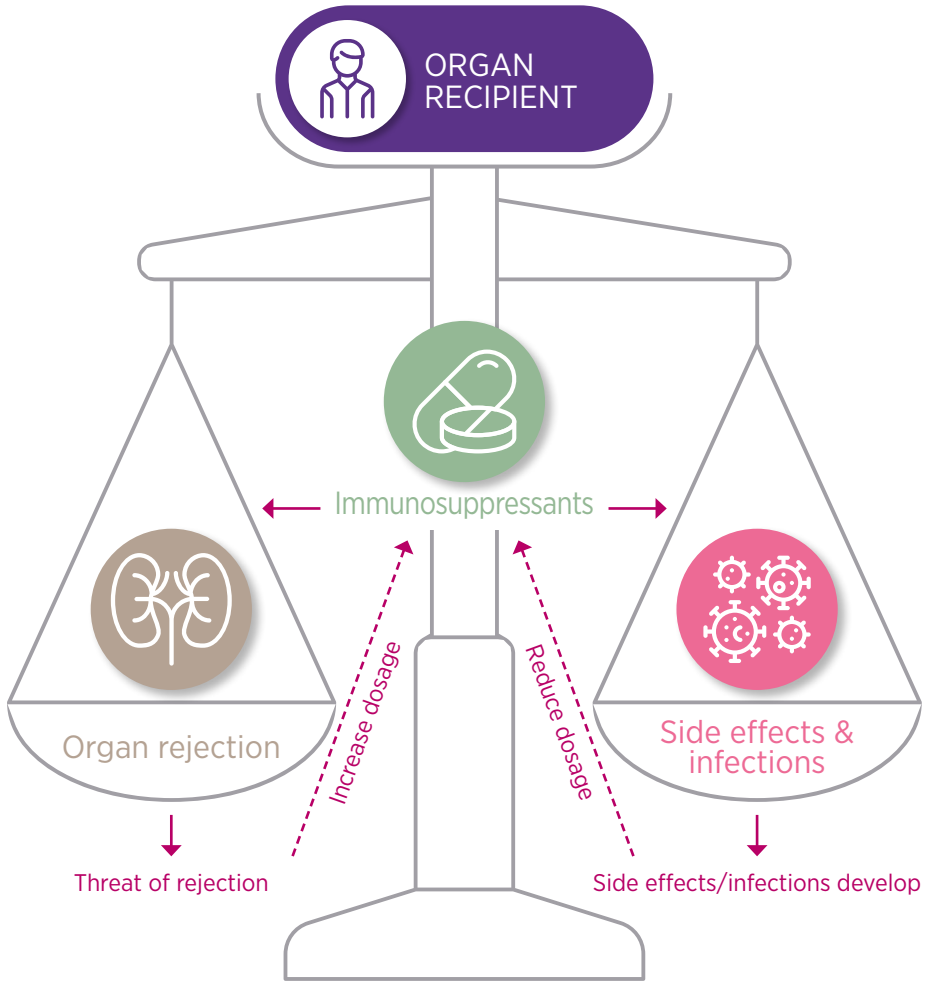
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Immunosuppressants – my lifelong companions

Why do I have to take medication?

- With the transplant, you've received an organ that your immune system, the body's own defence system, recognises as "foreign". With the help of drugs called immunosuppressants, the activity of the immune system can be reduced, which lowers the risk of your body rejecting the new organ.
- Since the immune system is responsible for fighting infections caused by viruses, bacteria and fungi, it shouldn't be weakened too much.
- Finding a balance between the risk of rejection and infection is of utmost importance when being treated with immunosuppressants.
- Fever is an alarm signal from your immune system that can indicate either rejection or infection. Pay attention to your body's signals and keep in mind it's better to be safe than sorry – seek medical advice or contact your transplant centre if necessary.
- To maintain the delicate balance of the immune system, it's important to keep the active ingredient levels of the immunosuppressants in the blood stable. For this purpose, their levels are regularly checked by blood sampling. **This is why it's important that you attend your check-up appointments regularly.**





What should I keep in mind when taking medication?

- Always follow the instructions given by your transplant centre so that the immunosuppressants can work in the best way possible.
- Always ensure you're taking the correct dosage of your medication as well as observing the correct amount of time between doses.
- Some immunosuppressants must be taken while fasting or during or after a meal, as a high-fat, high-carbohydrate or high-protein diet can affect active ingredient levels.
- You should never pause or stop taking your medication regularly without first consulting your transplant centre.
- Diarrhoea or vomiting may affect the active ingredient levels. In the event that your symptoms do not subside after a short time, contact your transplant centre.
- If in doubt, it's better to be safe than sorry – don't hesitate to contact your transplant centre.

Taking your immunosuppressants correctly is the best way to protect your new organ.

The right dosage



The correct timing in relation to meals



Leaving the correct amount of time between doses



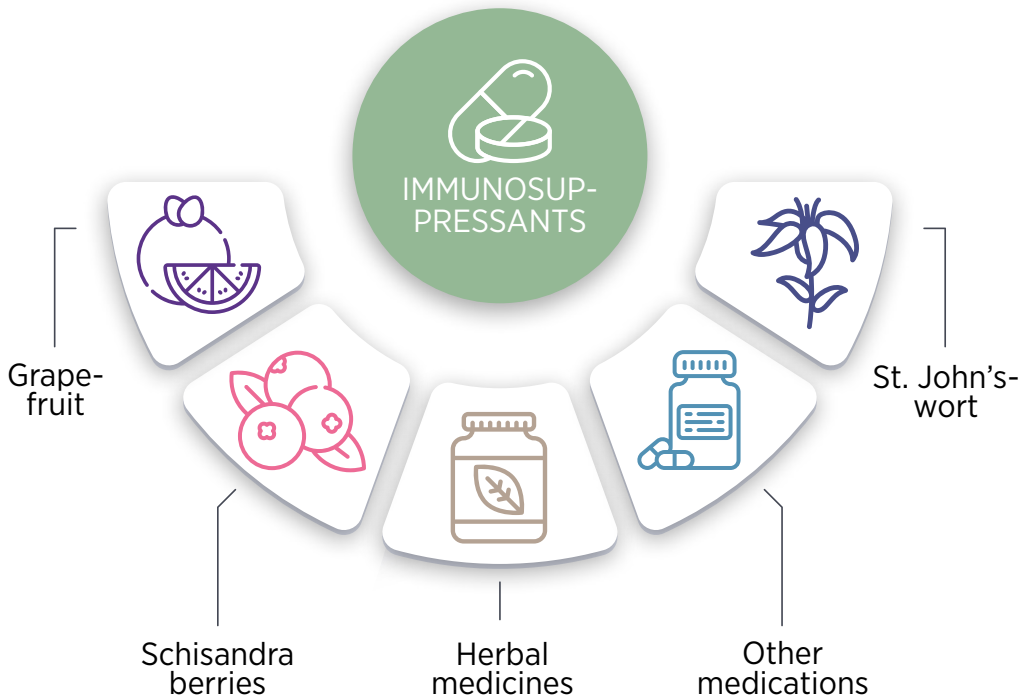
Regular checks



Can other medicines affect the effectiveness of my immunosuppressants?

- Certain drugs (e.g. so-called CYP3A4 inhibitors or inducers) can change the active ingredient levels of the immunosuppressants. These include medicines to treat viral or fungal infections, cancer medication, painkillers (e.g. lidocaine, fentanyl and metamizole) as well as antibiotics.
- Herbal medicines can also influence the effectiveness of immunosuppressants. These include in particular products containing St. John's-wort (*Hypericum perforatum*) or schisandra berries (*Schisandra sphenanthera*). Grapefruits can also have an influencing effect.
- Always talk to your transplant centre before taking other medicines (including over-the-counter ones) or herbal medicines.

What can influence the effectiveness of immunosuppressants?





Other medications, herbal medicines and certain foods can affect the effectiveness of immunosuppressants.

Can my diet influence the effectiveness of my immunosuppressants?

- Eating grapefruit can increase the active ingredient levels of immunosuppressants. For this reason, avoid eating fresh grapefruit and products containing grapefruit (e.g. multi-fruit juices).
- St. John's-wort, (*Hypericum perforatum*), which can be a component of herbal teas or sweets, for example, can lower the active ingredient levels of immunosuppressants and should therefore be avoided.
- Schisandra berries (*Schisandra sphenanthera*) can increase the active ingredient levels of immunosuppressants. Tea blends, muesli and other products containing these berries should not be consumed.
- Alcohol can impair the effectiveness of medicines and is particularly harmful to the new organ after a liver transplant. For this reason, you should avoid consuming alcohol.
- Since certain food components such as fats, carbohydrates or proteins can influence the active ingredient levels, the recommendation for taking the medication before, during or after a meal should always be followed.



Protection against infections

Why should I protect myself against infections in particular?

- Immunosuppressants reduce the activity of the immune system, our body's own defence system, against pathogens such as viruses, bacteria and fungi. This makes you more susceptible to infections after having a transplant.
- The early stage after a transplant is particularly critical, as a higher dose of immunosuppressants is taken during this period.
- The most important measures to protect yourself against becoming infected are summarised below. You can also find this and further information in our "Protection against infections" brochure and on www.transplant-wissen.de.

Taking immunosuppressants reduces your body's defences against pathogens. You can protect yourself from this as well!



How can I protect myself against infections?

Adhering to kitchen hygiene

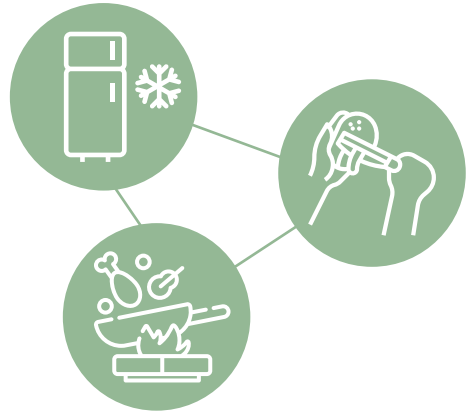
- Because of the way food is handled, the kitchen is a place where pathogens are more prevalent. However, by taking certain hygiene measures you can keep the risk of infection as low as possible:
 - Washing hands before and after handling food
 - Washing tea towels at at least 60°C
 - Replacing dishcloths and sponges regularly
 - Thorough cleaning of work surfaces and cooking utensils
 - Using a glass or ceramic chopping board (wooden or plastic boards facilitate the accumulation of bacteria).
 - Regular basic cleaning of the refrigerator
 - Observing the best-before date on foodstuffs

Careful cleaning is the most important thing when it comes to kitchen hygiene.

Hygienic food handling

- Food provides a good breeding ground for bacteria and fungi. However, hygienic handling and adherence to a low-bacteria diet can reduce the risk of infection.
- **Purchase:** Small quantities, preferably fresh or vacuum-packed with a long best-before date.
- **Transport:** Pack chilled and frozen products in cool bags; raw meat and raw fish must be kept separately

- **Storage:** Store all food in a cool and dark place; perishable products should be in closed containers in the refrigerator.
- **Preparation:**
 - Wash fruit and vegetables thoroughly and peel them if possible.
 - Always cook fish and meat thoroughly

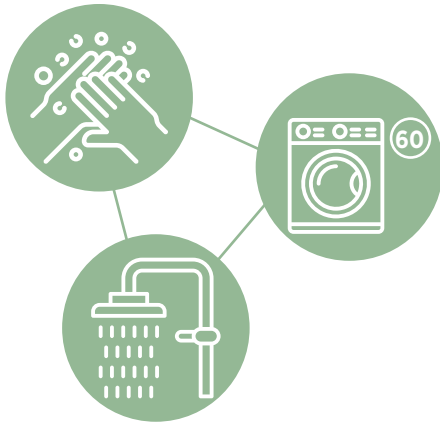


From purchasing to preparation – you have to pay attention to hygienic food handling at all stages.

Which products are suitable for a low-bacteria diet and which are not?

- Consume pasteurised dairy products and well-cooked meat and fish. Avoid raw foods such as raw milk, raw milk products (e.g. Camembert, Gruyère, Tilsiter), fish (e.g. in sushi), meat and eggs.
- Lettuce and sprouts are not suitable because they're often contaminated with bacteria.
- Nuts may contain fungal spores and should only be purchased if they've been heated, shelled and vacuum packed. However, transplant centres often recommend limiting the consumption of nuts to only those baked in cakes and biscuits.
- Boiled tap water and commercially bottled drinks are suitable for drinking. Water from drink dispensers, such as those often found in clinics, doctors' surgeries and pharmacies, should not be consumed.





Adhering to careful personal hygiene

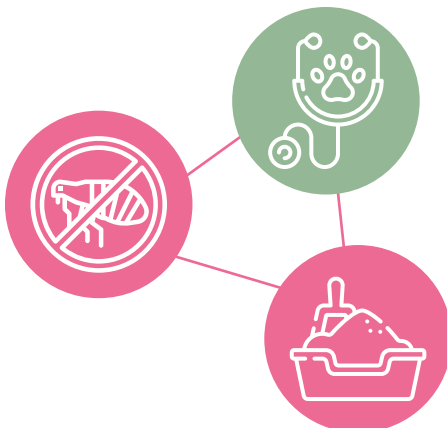
- Our skin and mucous membranes are naturally colonised with microorganisms, such as bacteria, and also come into contact with pathogens during everyday life. Thorough personal hygiene is therefore essential to protect against infections.
 - Regular hand washing
 - Thorough oral hygiene; brushing teeth at least twice a day (dentures once a day)
 - Daily intimate hygiene
 - Showering is better than a full bath
 - Washing hand towels at at least 60°C

Precautions for taking care of plants



- Plants and soil are colonised with numerous microorganisms. To protect yourself against infections, you should follow a few rules when taking care of plants:
 - Wear gloves to avoid skin injuries that would allow bacteria to penetrate the skin
 - Observe thorough hand washing after handling plants and soil
 - Avoid dust formation, e.g. by using planting substrate instead of soil, or wearing a face covering

Rules to follow for handling pets

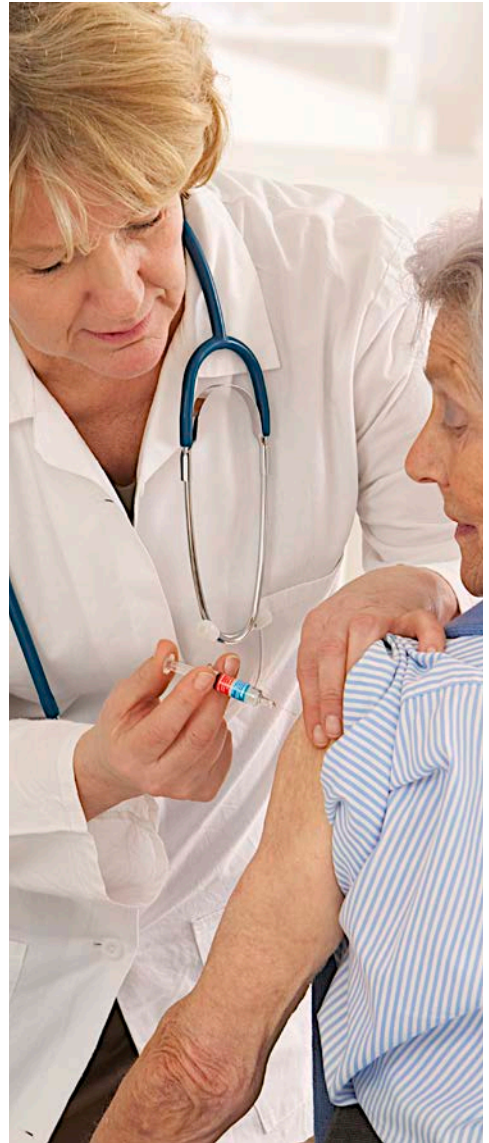


- If you already have a pet, in principle you don't have to give it up after the transplant. A few rules to follow will help you to reduce the risk of infection:
 - Wash your hands after touching the animal
 - Regularly take your pet for a veterinary check-up to ensure they don't have parasites or worms
 - Avoid contact with animal excrement, e.g. don't clean out the litter tray yourself.
 - Don't touch stray animals
- Getting a new pet is discouraged by most transplant centres, at least in the first 1-2 years after having the transplant.

- Some pets carry an increased risk of infection, as they are often carriers of certain infectious pathogens. These include cats (*Toxoplasmosis*), parrots (*psittacosis*) and reptiles (*salmonellosis*). In general, young animals in particular are carriers of numerous pathogens, often without showing symptoms themselves.

Protection through vaccinations

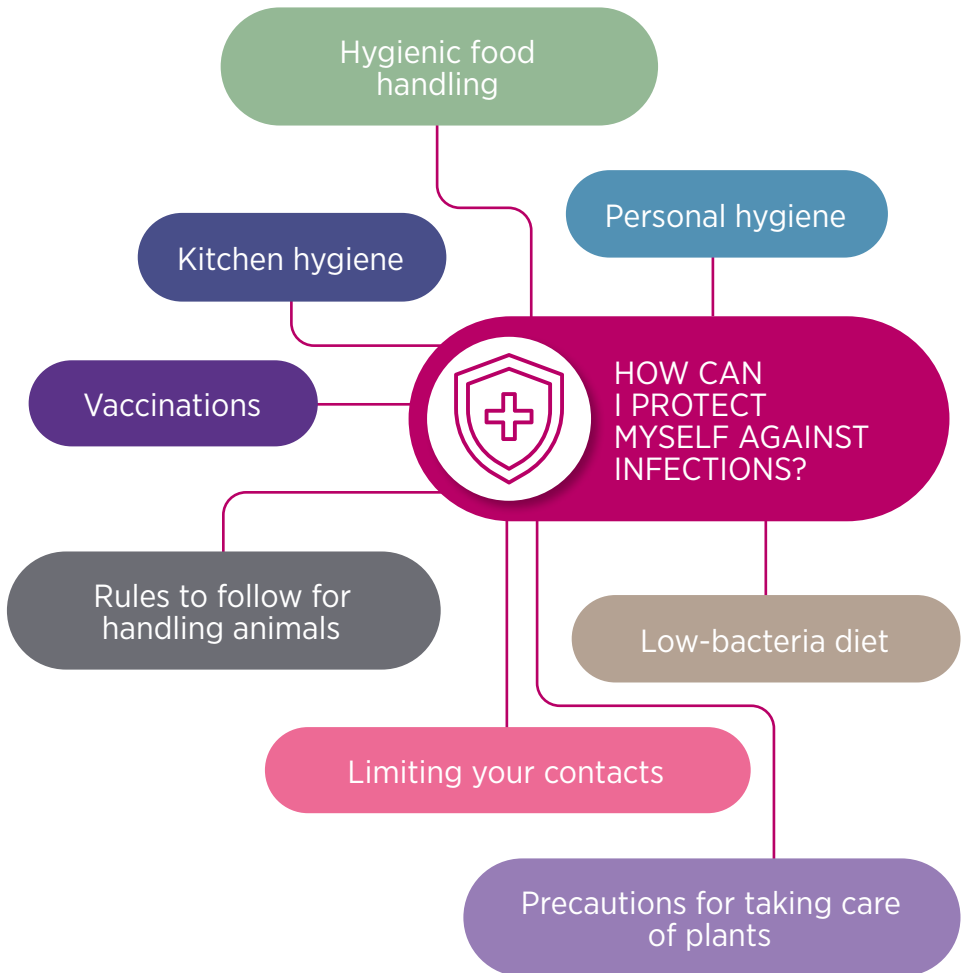
- Regular vaccinations against certain pathogens protect against infections.
 - In general, getting vaccinated against diphtheria, tetanus and influenza (flu) is recommended.
 - In certain cases, getting vaccinated against pneumococcus, early summer meningoencephalitis (TBE), meningococcus, rabies and polio-myelitis (no oral vaccination) may also be useful after consultation with the transplant centre.
 - Vaccination against SARS-CoV-2 (COVID-19 illness) is possible after prior consultation with the transplant centre.
 - Vaccination against herpes zoster is possible and thus prevents the occurrence of painful shingles.
- Please bear in mind that immunocompromised persons must not receive live vaccines. Therefore, always inform your doctor about your immunosuppression.
- If your closest contacts are comprehensively vaccinated, this also contributes to protecting you against infections.
- Some vaccinations are required for travelling to certain destinations. In any case, contact your transplant centre about this.



Vaccinations effectively protect you against infections! Talk to your doctor about this!

Limiting your contacts

- To avoid becoming infected, contact with people with infectious diseases should be restricted as far as possible.
- Avoid large gatherings of people to minimise the risk of infection.



Recreational activities

Sport and movement

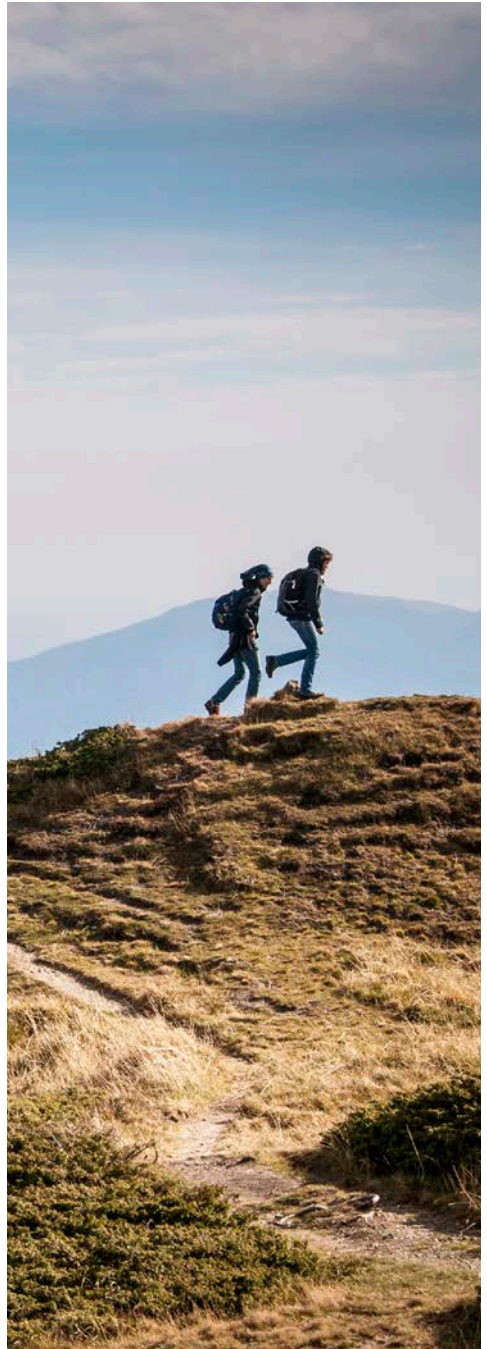
- Physical activity has numerous positive effects on physical as well as psychological wellbeing and is therefore also hugely important after a transplant.
- Enjoy being active again and integrate exercise into your daily life.
- Endurance sports or sports that are easy on the body are well suited. On the other hand, sports that involve a great deal of physical exertion or an increased risk of injury are not recommended.
- If you are unsure which kind of sporting activity is right for you, talk to your transplant centre.
- You will find more information on the topic of exercise in everyday life and sport in our “Active Living” brochure and on www.transplant-wissen.de.



Holidays and travelling

- Travelling is generally possible even after a transplant.
- Some measures help to minimise health risks on a trip:
 - Selecting the right travel destination (pay attention to good medical care and hygienic standards; avoid regions with a high risk of infection, e.g. malaria and cholera areas).
 - Good travel planning including getting vaccinated and seeking travel medicine advice
 - Adhering to hygiene and prophylactic measures (e.g. sun protection, insect repellent) when at the destination
- Taking regular immunosuppressants should also be a top priority when on holiday. It is advisable to carry a reserve of medicines and to carry medicines in your hand luggage.
- If you would like to find out more about holidays and travelling, take a look at our “Active Living” brochure and on www.transplant-wissen.de.

With good planning and by observing important behavioural rules at the destination, you can enjoy travelling.





Sexuality and family planning

- In principle, a fulfilling sex life after a transplant can be enjoyed without any concerns. In terms of time, this depends on how quickly the wound heals and, after a kidney transplant, also on when the ureteral stent is removed.
- The new organ can have a positive effect on sexual function.
- However, physical and psychological discomfort caused by the transplant or as a side effect of the medication can also affect your sex life. In many cases, however, there are options for treating this. Talk to your doctor about this.
- Barrier methods such as condoms or a diaphragm are recommended for contraception. Condoms also offer protection against sexually transmitted infectious diseases.
- If you are planning to conceive a child, discuss this with your transplant centre as early as possible.
- Under certain conditions, a successful pregnancy is also possible after having a transplant.
- We have compiled further information for you in the “Sexuality and family planning” brochure.

Glossary

- **Active ingredient levels:** The amount of a medicine that is in the blood at any given time
- **Antibiotics:** Medicines to treat an infection caused by bacteria
- **COVID-19:** Infectious illness caused by the SARS-CoV-2 coronavirus, which affects the respiratory tract especially and can be both asymptomatic as well as fatal.
- **CYP3A4 inhibitors and inducers:** Cytochrome P450 3A4 (CYP3A4) is an enzyme (protein) that occurs mainly in the liver in humans. There it's responsible for the metabolism and therefore the degradation of various poorly water-soluble substances. As well as this, immunosuppressants are also broken down by this pathway, consequently the activity of CYP3A4 influences the active ingredient levels of immunosuppressants. CYP3A4 inhibitors suppress the activity of the protein and increase active ingredient levels. CYP3A4 inducers increase the activity of the protein and, thus, lower the active ingredient levels.
- **Diphtheria:** Infectious disease caused by bacteria that affects the throat, larynx, tonsils and nose, as well as the skin, and can have severe consequences.
- **Early summer meningoencephalitis (TBE):** Infectious disease triggered by a virus, which can lead to inflammation of the entire brain or the meninges; transmitted by tick bites
- **Herpes zoster:** Infectious disease caused by viruses, known as shingles, which can occur a long time after having chickenpox, triggered by the same virus
- **Immunosuppressants:** Medicines that reduce the activity of the body's own defence system (immune system)
- **Influenza:** Infectious disease commonly known as the flu, which is caused by a virus and can vary in severity.
- **Meningococcus:** Bacteria that can cause life-threatening inflammation of the meninges if they become infected
- **Pneumococcus:** Bacteria that are responsible for a large proportion of pneumonia cases in adults and can also cause inflammation of the sinuses, middle ears or meninges.
- **Polio** **myelitis:** Infectious disease known as polio, which is caused by viruses and can lead to permanent paralysis.
- **Prophylaxis:** Measures carried out to prevent diseases
- **Rabies:** Infectious disease caused by a virus transmitted from animals to humans, usually fatal; vaccination is recommended when travelling to risk areas and specific exposure
- **SARS-CoV-2:** Scientific name of the coronavirus that has been spreading worldwide since 2020.
- **Tetanus:** Also known as lockjaw, an infectious disease caused by bacteria and characterised by severe muscle spasms

Additional information

AKTX Pflege e. V.

<https://www.transplantationspflege.de/>

Arbeitskreis Nierentransplantation
(Kidney Transplantation Working Group)

<http://www.nieren-transplantation.com/>

Auswärtiges Amt – Reise- und Sicherheitshinweise
(Federal Foreign Office – Travel and Safety Information)

<https://www.auswaertiges-amt.de/de/ReiseUndSicherheit/reise-und-sicherheitshinweise>

Bundesverband der Organtransplantierten e. V.
(Federal Association of Organ Transplant Recipients)

<https://bdo-ev.de/bdo/>

Bundesverband Niere e. V.
(Federal Kidney Association)

<https://www.bundesverband-niere.de/informationen/transplantation>

Bundeszentrum für Ernährung
(Federal Centre for Nutrition)

<https://www.bzfe.de/>

Bundeszentrale für gesundheitliche Aufklärung
(Federal Centre for Health Education)

<https://www.organspende-info.de/>
<https://www.infektionsschutz.de/>

Bundesverband für Gesundheitsinformation und Verbraucherschutz – Info Gesundheit e. V.

<http://www.bgv-transplantation.de/danach.html>

Centrum für Reisemedizin
(Centre for Travel Medicine)

<http://www.crm.de/>

Deutsche Gesellschaft für Ernährung e. V.

<https://www.dge.de/>

Deutsche Gesellschaft für Nephrologie e. V.
(German Nephrology Society)

<https://www.dgfn.eu/>

Deutsche Gesellschaft Rehabilitationssport für
chronisch Nierenkranke e. V.

<http://reni-online.de/transplantierte/>

Deutsche Gesellschaft für Tropenmedizin,
Reisemedizin und Globale Gesundheit e. V.
(German Society for Tropical Medicine and
International Health)

<https://www.dtg.org/>

Deutsche Leberstiftung
(German Liver Foundation)

<http://www.deutsche-leberstiftung.de/>

Deutsche Stiftung für Organtransplantation
(German Organ Transplant Foundation)

<https://www.dso.de/>

Deutsche Transplantationsgesellschaft e. V.
(German Transplant Society)

<http://www.d-t-g-online.de/>

Eurotransplant

<http://www.eurotransplant.org/>

International Transplant Nurses Society

<http://itns.org/>

Junge Nierenkranke Deutschland e. V.
(Young Kidney Patients, Germany)

<https://juniev.de/>

Kuratorium für Dialyse und Nierentransplantation e. V.
(Dialysis and Kidney Transplant Advisory Board)

<https://www.kfh.de/>

Lebertransplantierte Deutschland e. V.

<https://lebertransplantation.eu/>

Robert Koch-Institut (RKI)

<https://www.rki.de/>

Stiftung Über Leben – Initiative Organspende

<https://www.ueber-leben.de/>

Ständige Impfkommision

https://www.rki.de/DE/Content/Kommissionen/STIKO/stiko_node.html

Transdia Sport Deutschland e. V.

<https://transdiaev.de/>



www.transplant-wissen.de

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