

Live an active life Life after a transplant

Foreword

Dear patient,

we wish you all the best for the future after your organ transplant. In this brochure, we would like to make your transition to an active everyday life after your transplant easier. This is because it is important, particularly now, after you have probably been waiting a long time for your new organ and have numerous hospital stays behind you, that you reinforce the health of your new organ and your whole body with an active lifestyle. The correct amount of sport and exercise have a positive impact on health and should, therefore, be an integral part of your daily routine.

The following pages also contain tips for you on returning to every-day working life, as well as general recommendations for planning holidays and travel. As each patient who has received a transplant has a completely unique history, we strongly recommend that you work very closely with your transplant centre and the doctors providing your treatment.

Please remember that individual and centre-based approaches may vary and not all the advice provided here is universally applicable.

We wish you all the best with your new donor organ.

Yours sincerely,

Kerstin Herzer and Flisabeth Schieffer

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Introduction -Being active after your transplant

Life for patients before a transplant, e. g. kidney or liver, is mostly associated with significant restrictions in their daily routine and how they live their lifes in general.

Thanks to receiving a donor organ, it will be possible to plan your everyday life independently and more self-determined and active again:

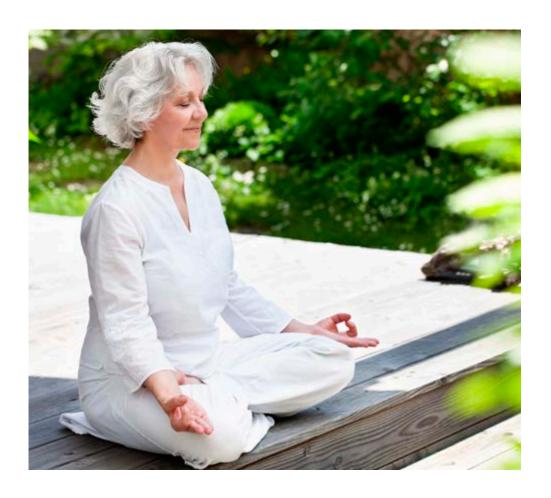
- Your physical capacity (strength, endurance and speed of movement) will be improved.
- Considering some dos and don'ts will now allow you to largely normalise your daily routine.

- You will regain your independence (e.g. reduced number of appointments with your doctor and at the hospital).
- You can start to pursue your career and plan your leisure activities again.

This information brochure will give you advice on how to structure your active daily routine and on your return to a more independent and self-determined life after your transplant. It will give you an overview of which (physical) activities are recommended and which precautions to take in this regard.

With a little practice, your physical capacity will improve significantly!





Sport and exercise

Why are physical activities important?

- Physical activity promotes wellbeing and improves your health.
- It helps you to find a daily balance and to combat stress, and to maintain a stable body weight or, if necessary, also to reduce it.
- Physical activity counteracts the development of <u>osteoporosis</u> and has a positive impact on your metabolism. This is particularly advantageous as blood sugar levels may increase in patients taking <u>immunosuppressants</u>, with a consequently higher risk of developing diabetes.

How soon can I resume physical activities after my transplant?

- Early mobilisation is very important after transplant surgery; therefore, you should incorporate physical exercise such as walks, into your daily routine. Pedometers can be helpful in this regard. Some health insurance providers already provide these devices; however, nowadays it is also possible to measure the number of steps you take every day using your mobile phone.
- You should avoid strenuous exertion and heavy lifting after your transplant, as your wound has not yet completely healed.
- The point at which you begin physical activity after your transplant depends on how you feel, on
 the transplant organ and on your general state of
 health. If you have already been able to improve
 your condition by regular walking, then exercising using an ergometer/home trainer, walking or
 cycling in the open air are also options.
- Discuss this with the doctor providing your treatment and the transplant centre, and draw up an exercise plan together.

Physical activity promotes well-being and improves your health!





What should I be aware of when undertaking physical activity after a transplant?

- Physical activity is highly recommended, but start gradually and initially under specialist supervision and guidance.
- The extent to which you are active should be based on your physical condition.
- It is recommended that you increase physical activity slowly. Muscles may have become significantly weakened and a certain amount of bone loss may have occurred as the result of long-term lack of exercise and frequent <u>dialysis</u> appointments (kidney transplant recipients).
- In addition, the intake of certain <u>immunosuppressants</u> (e.g. <u>corticosteroids, tacrolimus</u>) increases
 the risk of developing <u>osteoporosis</u> and consequently of broken bones.
- The intensity of physical exertion should be based on blood pressure and heart rate. The use of heart rate monitors is an option in order to monitor your active heart rate during physical activities. Talk this over with your doctor.
- Drink sufficient quantities of liquids and remember to wear sunblock when you are engaged in physical activity outside.

Compensate for the loss of liquid during sport with the adequate intake of fluids!



How much physical exertion can I withstand?

- The extent of physical exertion depends on your capacity.
- Avoid lifting or carrying heavy weights to protect your new organ.
- In this respect, seek the advice of your treating doctor, physiotherapist or sports physician.



What types of physical activity can I engage in?

- · Take long walks and hikes.
- In principle, endurance sports are recommended after consultation with your doctor (e.g. walking, cycling or slow jogging etc.).
- Swimming is an option after your wound has healed completely; however, be conscientious about adequately disinfecting your hands and feet after using the sauna, swimming pool and public water facilities.



By leading an active daily life and engaging in appropriate physical activities, you will be able not only to increase your physical capacity and quality of life but also improve your prognosis.

Therefore: Incorporate physical exercise into your daily routine!



- Leave the car behind and go on foot or take your bike.
- Use the stairs instead of the lift.
- Avoid sitting for long periods. Stand up after two hours at the most and move around.
- · Perform short exercises at your desk.

Which types of sport should I be careful of engaging in?

- As a transplant recipient, caution is advisable in relation to sports with a higher risk of injury and falling, depending on experience and intensity (e. g. combat sport, riding, alpine skiing etc.).
- Be careful of sports with uncontrolled movement, the use of objects (e.g. tennis racquets, balls etc.) or involving significant physical exertion
- Blows or concussion can lead to your new organ being damaged.

Sport types



When should I avoid participating in sport? Avoid participating in physical activities in the event of ...

- · high outdoor temperatures
- fever
- infections (even 1–2 weeks after an infection)
- pain
- extreme exhaustion/tiredness.

When should I interrupt physical activity? Stop your participation in physical activity in the event of ...

- · unusually fast heart rate
- · irregular pulse and pain in your chest area
- · shortness of breath
- · extreme sweating
- dizziness
- nausea
- · muscle cramps
- · disturbed vision.

Talk to your doctor if you experience symptoms during exertion!







How can I increase my motivation to participate in physical activities?

- Only regular training will lead to success! That is why it is important that you enjoy the type of sport you choose.
- Be conscious of your improved performance, as this will increase your motivation.
- Participate in sport with like-minded individuals in a group (e.g. with other organ transplant recipients) and at fixed times. If you are short of time, choose physical activities that you can also participate in at home. The important thing is to integrate regular participation into your daily routine.
- Ask your doctor about the option of participating in special training groups (e.g. "heart or lung group", function training) near where you live.



Return to the workplace



Can I pursue my professional career again after my transplant?

- The return to work life is very important for many transplant recipients, as it increases patients' physical and psychological quality of life. The reasons for this are:
 - regular occupation
 - success
 - social contacts.
- Avoid a job involving significant physical and mental exertion as well as an increased risk of acquiring an infection.

When will I be able to go back to work?

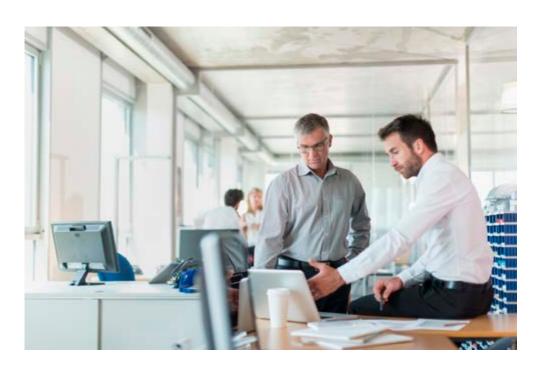
- Starting professional employment is dependent on the individual's state of health and their professional occupation. In principle, you can return to your profession as soon as you feel you are able to cope with it.
- Be careful to increase your working hours and exertion level slowly.
- · Avoid excessive physical exertion and stress.



Which requirements should my work-place fulfil?

- As much as possible, design your daily working routine so that you get enough sleep and are able to ensure that you take your medication regularly.
- Your workplace should be clean and free of dust.
- Avoid offices with air-conditioning systems, as they present an increased risk for the spread of bacteria.
- Avoid working in conditions involving extreme heat and exposure to toxic substances that can cause liver damage.
- Be careful about increased exposure to sunlight e.g. outside occupations. Due to the <u>immuno-suppressive</u> treatment, you are at higher risk of developing skin cancer.

A professional occupation in a low-infection environment will improve your physical and psychological quality of life!





Holidays and travel

Will I be able to travel after my transplant?

- In principle, it is possible to travel if you consider certain do's and don'ts.
- However, in the first year, you should choose travel destinations close to home or offering adequate medical care and a good standard of hygiene, as you are still at an increased risk of developing complications.

What should I be aware of when travelling on holiday?

- Ideally, you should select a travel destination where you can access good medical care and your medication is available, and which employs German-speaking doctors.
- Ask your treating doctor or tropical/travel medicine specialist about possible risks before the start of your foreign travel.

- Where a time change is involved, you should discuss your medication intake beforehand with your treating doctor.
- Follow the current vaccination recommendations by the Ständige Impfkommission (Standing Committee on Vaccination) (STIKO) for your destination country. Contact your treating doctor or tropical/travel medicine specialist.
- Travelling in regions where malaria is endemic and where hygiene conditions are poor (gastrointestinal infections) is generally associated with an increased risk of infection. However, if you still wish to travel, talk to your doctor and, in particular, enquire about a course of malaria tablets.
- You can protect yourself even more when you are travelling by taking appropriate preventative measures such as mosquito repellent, light and long clothing, air-conditioning and mosquito nets.
- Avoid tap water and raw food, unpeeled fruit and vegetables, as well as salad that has been washed using tap water.
- Don't clean your teeth with tap water, instead only use water from industrially filled bottles.
- Avoid direct sunlight on your skin by wearing long clothing. Wearing adequate sunblock offers additional protection against ultraviolet (UV) rays. Particularly in equatorial regions, UV radiation levels are considerably higher than at our latitudes.

Checklist for your trip:

- ☐ Timely planning and preparation
- Report on current laboratory results and diagnoses (medical letter), vaccination passport, medical certificate regarding prescribed medication and transplant ID card
- ☐ Medication reserves (note storage instructions)
- ☐ Carry medication in hand luggage
- Clarify insurance cover abroad (possible repatriation in the event of illness)
- ☐ Clarify vaccination status depending on destination country
- ☐ Adequate sunblock and insect repellent

Travel is possible as long as you take adequate hygiene and preventative measures, prepare thoroughly for your journey and seek advice with regard to travel medicine!





^{*}Caution: air-conditioning may keep mosquitos at bay; however only limited use is recommended, as there is the risk of over-cooling and the proliferation of bacteria. **Caution: even mosquitos active during the daytime can transmit infectious diseases.

Glossary

- Dialysis: <u>Dialysis</u> or haemodialysis refers to a particular <u>dialysis</u> procedure during which the blood is transported out of the body through a semi-permeable synthetic membrane in order to remove certain substances. This therapy option is deployed as renal replacement therapy in acute and chronic cases of kidney failure.
- Immunosuppression: In <u>immunosuppression</u> therapy, the body's own immune system is artificially suppressed by taking special medication <u>immunosuppressants</u>.
- Corticosteroids: <u>Corticosteroids</u> are steroid hormones that are produced in the adrenal cortex from cholesterol or manufactured synthetically.
 They have an immunosuppressive effect.
- Osteoporosis: <u>Osteoporosis</u> refers to a medical condition in which the bones become weak and are susceptible to breakages.
- Tacrolimus: <u>Tacrolimus</u> is an <u>immunosuppressant</u> which is used to suppress the immune systems of organ transplant recipients.
- Ultraviolet (UV) rays: Ultraviolet (UV) rays are electromagnetic rays of a particular wavelength invisible to the human eye that are present in natural sunlight among other things.

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Further information

AKTX Pflege e. V.

https://www.transplantationspflege.de

Arbeitskreis Nierentransplantation https://www.nieren-transplantation.com

Auswärtiges Amt – Reise- und Sicherheitshinweise (Federal Foreign Office – Travel and Safety Information) https://www.auswaertiges-amt.de/de/ReiseUnd Sicherheit/reise-und-sicherheitshinweise

Bundesarbeitsgemeinschaft der Integrationsämter und Hauptfürsorgestellen (BIH) GbR (Federal Association of Integration Offices and Main Welfare Offices) https://www.integrationsaemter.de/Aktuell/ 72c6/index.html

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

Bundeszentrale für gesundheitliche Aufklärung (Federal Centre for Health Education) https://www.organspende-info.de

Bundesverband für Gesundheitsinformation und Verbraucherschutz – Info Gesundheit e. V. (Federal Association for Health Information and Consumer Protection – Health Information) https://www.bgv-transplantation.de/danach.html

Centrum für Reisemedizin (Centre for Travel Medicine) https://www.crm.de

Deutsche Gesellschaft für Nephrologie e. V. (German Nephrology Society) https://www.dgfn.eu

Deutsche Gesellschaft für Tropenmedizin, Reisemedizin und Globale Gesundheit e. V. (German Society for Tropical Medicine and International Health) https://www.dtg.org Deutsche Gesellschaft Rehabilitationssport für chronisch Nierenkranke e. V. (German Society for Rehabilitation Sport for Chronic Kidney Patients) http://reni-online.de/transplantierte

Deutsche Leberstiftung (German Liver Foundation) https://www.deutsche-leberstiftung.de

Deutsche Stiftung für Organtransplantation (German Organ Transplant Foundation) https://www.dso.de

Deutsche Transplantationsgesellschaft e. V. (German Transplant Society) https://www.d-t-g-online.de

Eurotransplant https://www.eurotransplant.org

European Kidney Patients' Federation (CEAPIR) https://www.ekpf.eu

International Transplant Nurses Society https://www.itns.org

Junge Nierenkranke Deutschland e. V. (Young Kidney Patients, Germany) https://juniev.de

KfH Kuratorium für Dialyse und Nierentransplantation e. V. (Dialysis and Kidney Transplant Advisory Board) https://www.kfh.de

Lebertransplantierte Deutschland e. V. (Liver Transplant Recipients, Germany) https://lebertransplantation.eu

Robert Koch Institut (RKI) https://www.rki.de Stiftung "Für das Leben" http://www.stiftung-fuer-das-leben.de

Ständige Impfkommission

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

Transdia Sport Deutschland e. V. https://transdiaev.de

Radtour pro Organspende https://www.radtour-pro-organspende.de

