Recipients

Version 1.1 – February 2023



CNDO Nationaler Ausschuss für Organspende Comité National du don d'organes

Team of authors: Prof Christian Benden MD, PD Franz Immer MD

Team of experts:

Dr. med. Isabelle Binet, Silvia Ciganek, Debora Jenni, Ramona Odermatt, Daniel Schärli, Marian Struker

© Copyright Swisstransplant/CNDO

All rights reserved. No parts of the Swiss Donation Pathway or associated materials may be reproduced, transmitted or transcribed without prior written permission from Swisstransplant / CNDO. www.swisstransplant.org

Contents

| 1.0 Preface 2.0 Summary 3.0 Recipients | | 4 |
|--|--|----|
| | | 5 |
| | | |
| 3.2 | Immunosuppression following transplantation | 8 |
| 3.3 | Infection prevention following transplantation | 10 |
| 3.4 | Vaccinations and vaccination recommendations | 11 |
| 3.5 | Complications following transplantation | 12 |
| 3.6 | Everyday life and work | 14 |
| 3.7 | Sport and sexuality | 16 |
| 3.8 | Travel following transplantation | 17 |
| 3.9 | Quality of life following transplantation | 20 |

1.0

Preface

The Swiss Donation Pathway guidelines and recommendations were developed to serve as a quality assurance programme with national basic standards for the donation process. They are intended for persons involved in the donation process as a training resource to meet the legal requirements set out in the Federal Act of 1 July 2007 on the Transplantation of Organs, Tissues and Cells (Bundesgesetz vom 1. Juli 2007 über die Transplantation von Organen, Geweben und Zellen).

The programme was established by the Swiss Foundation to Support Organ Donation (FSOD). In 2009, the programme was taken over by the National Committee for Organ Donation (CNDO).

The "Donor recognition, reporting and treatment of a DCD donor" module is part of the Swiss Donation Pathway. The Swiss Donation Pathway is based on the critical pathway for organ donation following brain death.

The modules consist of:

- 1. Basisversion: Donor recognition: legal basis and relevance in practice
- 1. Donor recognition SOP
- 2. Taking care of next of kin and communication
- 3. Adult donor treatment: Intensive care unit
- 4. Paediatric donor treatment
- 5. Coordination and communication in the organ donation process
- 6. Guidelines for anaesthetic organ protection during organ procurement from adult donation after brain death (DBD) donors
- 7. Organ and tissue procurement from DBD donors
- 8. Transport Organization
- 9. Identification, reporting and treatment of a DCD donor
- 10. Recipients
- 11. Tissue donation: Cornea

The Swiss Donation Pathway is a joint project of the Swiss Society of Intensive Care Medicine (SSICM) and CNDO / Swisstransplant. The recommendations have been developed by, among others, intensive care physicians belonging to the expert group of the CNDO.

In 2020, the modules were reorganised and their content revised. A second revision was made in 2023.

The term "organ donation" refers to tissue donation wherever appropriate.

2.0 Summary

Today, transplantation of solid organs is a well-established treatment option for patients with advanced heart, liver, lung or kidney diseases, for example, and for whom no long-term or other alternative medical or surgical treatment options are available.

Organ transplantation is subject to strict legal requirements that are governed nationally by the Swiss Transplantation Act and corresponding statutory regulations. In addition to the availability of sufficient donor organs of the necessary organ quality, the prerequisite for a lasting, successful organ transplantation is the careful selection of possible organ transplant candidates and long-term care for the transplant patients by interdisciplinary teams with experience in transplant medicine for specific organs. The term "transplant medicine" was coined by Rudolf Pichlmayr (1932 – 1997), a leading German transplant medicine specialist.

Transplantation to replace body functions and body parts has fascinated people for centuries. Transplantation even has some mystical origins as well. Advances in transplantation are very closely tied to developments in the medical field. At the beginning of the twentieth century, the Swiss surgeon Emil Theodor Kocher was awarded the Nobel Prize in Medicine. At the end of the nineteenth century, he had grafted thyroid tissue into a patient who had recently undergone thyroid surgery. The first kidney transplantation was then performed in 1933, but the recipient survived only a few days due to a transplant rejection. The recipient of the world's first heart transplant under the direction of South African cardiac surgeon Christiaan Barnard in 1967 in Cape Town also survived for less than three weeks. Organ rejection appeared to be an insurmountable obstacle to success in transplant medicine. The outcome was also similar for the recipient of the first heart transplantation in Switzerland, which was performed by the Swedish surgeon Åke Senning in Zurich in 1969.

Successful kidney transplantations began to be performed at Swiss centres around 1969. Pioneers in the field of transplant medicine include the Swiss surgeon Felix Largiadèr, who in 1973 succeeded in performing the first combined kidney and pancreas transplantation in Europe. It was not until 1992 that the first lung transplantation was successfully performed by Walter Weder at University Hospital Zurich.

The description of human leukocyte antigens (HLA) beginning in the 1950s by Jean Dausset and the discovery of the HLA system and histocompatibility in the 1960s were important milestones for tissue and organ transplantation. The active agent cyclosporine was discovered in 1970, marking a major advance in transplant medicine. Cyclosporine is derived from fungus and was discovered by two researchers named Jean-François Borel and Hartmann Stähelin from the Swiss pharmaceutical company Sandoz in Basel. This marked the point at which it was acknowledged that preventing the body's rejection of the transplanted organ is the fundamental criterion for a successful transplantation. Cyclosporine was used for organ transplantation for the first time by Roy Calne at Cambridge University in England in 1978. The first cyclosporine-based immunosuppressants were approved in the 1980s.

Today, just over 570 solid organ transplantations are performed in Switzerland each year. In 2022, most of these were kidney transplants (well over 300), followed by liver transplants (142), lung transplants (51), heart transplants (51) and pancreas transplants (13). These organ transplantations are performed at the six Swiss transplant centres in Basel, Bern, Geneva,

Lausanne, St. Gallen and Zurich as part of a mandate under the Intercantonal Agreement on Highly Specialized Medicine (IVHSM) in Switzerland.

Ultimately, however, it is not only the goal of organ transplantation to prolong a patient's life but also to improve the recipient's quality of life in the short, medium and, ideally, long term. In addition to the necessary follow-up care provided by experienced transplant medicine teams, organ transplantation also permanently affects patients' everyday lives. This document aims to address these and several other aspects in detail.

3.0

Recipients

3.1 Outcomes following solid organ transplantation

Today, solid organ transplantation is a widely accepted treatment performed on thousands of patients worldwide. Fortunately, the outcomes following organ transplantation have greatly improved since its early days in the last century. As a result, patients who are carefully selected for organ transplantation not only live longer in general but also enjoy a better day-to-day quality of life. All patients who have undergone organ transplantation have been included prospectively in the "Swiss Transplant Cohort Study" (STCS) since 2008 – provided they have given their consent. Collecting this data in a national registry serves the purpose of quality control and to assess outcomes, including their comparison with organ transplantation are at least at a level comparable to – or usually even above – international outcomes. All six transplant centres in Switzerland have agreed to publish the outcomes following their organ transplantations.

The STCS Annual Report 2020 includes all patients who received organ transplants between 1 May 2008 and 31 December 2019. Single as well as multiple organ transplantations (e.g. combined liver-kidney transplants) were included in the report. In addition to the first organ transplantation, any re-transplantation (e.g. a second kidney transplant after organ failure of the first transplanted kidney), as well as secondary organ transplantations (e.g. a kidney transplantation following previous heart transplantation), were included as well. According to the STCS Annual Report 2020, a total of 5018 patients were included following organ transplantation, 95% of whom underwent single organ transplantation; 90% of patients had received a first organ transplantation. A total of 9% of registered patients had undergone re-transplantation. Of the 3196 registered kidney transplant patients, 86% had received their first organ transplantation and 13% underwent re-transplantation of a kidney. Re-transplantation is rather uncommon in heart, liver or lung transplant recipients. Of the 238 registered double organ recipients, the majority had undergone combined kidney and pancreas transplantation (43%). The most organs were transplanted at University Hospital Zurich (2040 organs, 36.4%); the fewest at the St. Gallen cantonal hospital (211 organs, 3.8%, exclusively kidneys). The median patient age was 54. Nearly 64% of all patients were men, and only 5.2% were paediatric patients. Around 15% of registered patients died during the observation periods. The overall mortality rate of the patient cohorts, meaning death both with and without transplant failure, was 5.5% after one year and 25.5% after ten years (see Figure 1). The average

five-year survival rate in the patient cohort was more than 85% for all organs, whereby there were significant differences depending on the transplanted organ. Patients who underwent a kidney or combined kidney-pancreas

transplantation had an average five-year survival rate of over 90%; the average was 65% for lung transplant patients. In the latter case, it should be noted that the underlying diagnosis as well as patient age (over or under 60 years of age at the time of transplantation) are relevant differences (see Figure 2).

Swiss Transplant Cohort Study – Annual Reports https://www.stcs.ch/publications



Figure 1



Time since Tpx (in years)



Time since Tpx (in years)

3.2 Immunosuppression following transplantation

To ensure sufficient organ function following transplantation, immunosuppressants must usually be taken for the rest of the patient's life to prevent the body from rejecting the transplanted organ. What is important here is that the patient regularly takes the immunosuppressants at the prescribed times of day to ensure effective immunosuppression and to prevent or minimize possible side effects.

As a rule, the goal is to keep the number of medications taken following transplantation as low as possible. Doses of medication should not be missed, and any side effects caused by the medications should be immediately discussed with the transplant team. All medications must be kept in a dry place and protected from direct heat and sunlight and out of the reach of children. The expiration dates of medications must be noted. Leave all immuno-suppressants in the blister pack until you take them and make sure that you have sufficient reserves. To ensure that you are able to take the drugs at regular times as required, it is advised to carry the next dose on you when you leave the house. Taking anti-inflammatory drugs (Brufen, Voltaren, Algifor, etc.) is not recommended and must first be discussed with the transplant surgeon. Due to possible drug interactions, herbal or plant-containing medications, so-called phytopharmaceuticals (e.g. St. John's wort), changes to medication must be discussed in detail with a physician experienced in transplant medicine or with the attending transplant team.

Immunosuppressants interact with the human immune system in different ways to prevent the body from rejecting a transplanted organ. Because of this mechanism, the most common side effect of immunosuppression is increased susceptibility to infection, meaning the patient is at greater risk for bacterial as well as viral and fungal infections. Immunosuppression generally involves taking a combination of various medications to improve effectiveness and reduce side effect. The treatment is modulated for the individual patient and, among other things, depends on the transplanted organ as well as the amount of time that has passed since transplantation.

What are referred to as calcineurin inhibitors (CNIs) are taken regularly after transplantation. These may include cyclosporine A (e.g. Sandimmun Neoral[®]) and tacrolimus (e.g. Prograf[®], Advagraf[®], Envarsus[®]), but this is only a partial list of drugs approved in Switzerland. What is crucial for CNIs to work is the concentration in the blood. The ideal levels in the blood are determined individually and adjusted over time as needed. Depending on the results from these ideal blood level measurements, the CNI dose may be adjusted by the transplant team. The most common CNI side effects include increased blood pressure and reduced kidney function as well as shaky hands, burning sensations in the hands and feet and increased body hair growth (especially with cyclosporine A) and hair loss (with tacrolimus). Today, tacrolimus is the CNI used in most cases following solid organ transplantation.

Another immunosuppressant is mycophenolate (Cellcept[®] or Myfortic[®]), which is usually taken twice a day, every 12 hours. Its most common side effects include nausea, diarrhoea, gastrointestinal problems, skin changes (wearing adequate sun protection is strongly recommended), and a decrease in white blood cell production, making the patient more susceptible to infection. In the past, azathioprine (Imurek[®]) was prescribed, but it has gradually been replaced with mycophenolate.

Another commonly prescribed drug, at least temporarily, following organ transplantation is cortisone, which is actually a hormone produced by the human body that affects the human immune system in different ways. Cortisone is sometimes also administered in higher doses temporarily if an acute rejection reaction occurs following solid organ transplantation. Possible side effects of cortisone may include water retention in tissue (oedema), increased appetite, weight gain, so-called "moon face", sleep disorders, irritability and/or nervousness, increased blood sugar, wound healing disorders, and, in the case of long-term use, increased brittleness of the bones (osteoporosis).

Other immunosuppressants, such as mTOR inhibitors (Rapamune® or Certican®) or betalacept (Nulojix®), are available and can be used in specific cases in combination or instead of the drugs just mentioned.

It should always be noted that immunosuppressants reduce the body's inflammatory response and that typical symptoms of a disease (e.g. redness, pain, fever) may be much less severe while taking them.

To ensure adequate functioning of a transplanted organ, lifelong immunosuppression is generally required as directed by a physician. It is always **strongly** recommended to discuss any changes to medications with the attending transplant medicine physician in order to prevent the occurrence of undesirable side effects or transplant rejection.

For optimal adherence, it is important to establish a good therapeutic relationship with transplant recipients from the outset. Special attention should be paid in terms of adherence to the following patient groups: teenagers and young adults, patients with a foreign language, people under pressure at work and pre-emptive kidney transplant patients.

3.3 Infection prevention following transplantation

As previously explained, immunosuppression is necessary after organ transplantation in order to prevent transplant rejection. However, immunosuppression increases the organ transplant patient's susceptibility to infection. For this reason, prevention (prophylaxis) against bacterial as well as viral and fungal infections after solid organ transplantation is an important part of patient management. This includes medications prescribed to prevent infection as well as general and specific vaccination recommendations for the transplant patient and general best practices and precautions for everyday life.

E.g. antibiotics are prescribed prophylactically for dental procedures in immunosuppressed patients. For infections of the respiratory system or urinary tract, for example, antibiotics are sometimes also prescribed at an early stage depending on the type of organ transplantation and degree of immunosuppression. The choice of antibiotics and duration of treatment is up to the transplant medicine physician. A different course of antibiotic treatment and treatment modality than what would be advised for a patient who has not received an organ transplant may be selected.

The antibiotic combination of trimethoprim and sulfamethoxazole (Bactrim[®], Nopil[®]) is often taken by patients following transplantation – sometimes for the rest of their lives – to prevent pneumocystis pneumonia, an opportunistic infection caused by the pathogen pneumocystis jirovecii. To protect against cytomegalovirus (CMV), the virostatic valgancyclovir (Valcyte[®]) is prescribed depending on whether a patient already has lifelong immunity to CMV due to a past CMV infection and depending on the CMV status of the organ donor. In most healthy people, a CMV infection usually has no or only minor symptoms of the disease. However, after transplantation with immunosuppression, a CMV reinfection or CMV reactivation can cause serious complications, such as CMV colitis (colon inflammation) or CMV pneumonia. Following organ transplantation, patients are also given antiviral medications for what are referred to as community acquired respiratory viral infections (CARVs). The drug oseltamivir (Tamiflu[®]) is one such drug that is used for treatment as well as prophylactically following exposure to the seasonal influenza virus, even for transplant patients who have previously

Fungal infections are another possible complication that occur in organ-transplant patients taking immunosuppressants. Depending on the type of organ transplantation, amphotericin B (Ampho-Moronal®) is prescribed prophylactically or to treat fungal diseases (yeasts and moulds) of the (oral) mucous membranes, oesophagus and intestine. Other antimycotics (antifungal drugs) belong to the group of azoles, which are used prophylactically and to treat systemic mycosis. These include itraconazole (Sporanox®), posaconazole (Noxafil®) and voriconazole (VFEND®), for example. The concomitant use of azoles and CNIs is known to cause interactions affecting CNI blood levels, meaning that azoles should only be taken when prescribed by the transplant medicine doctor. Careful CNI blood level monitoring is indicated to prevent undesirable side effects.

received a seasonal flu vaccination.

Adequate infection prevention also includes good bodily hygiene, meaning regular hand washing as well as good oral and dental hygiene, along with annual visits to the dentist. During flu season in winter, it is recommended to avoid attending large gatherings and being around sick individuals. Wash your hands thoroughly after any contact with pets. Wear gloves and a mask when cleaning cat litter boxes or bird cages. Injuries such as bites and scratches must be disinfected and a plaster must be applied. Check the wound regularly for signs of infection.

Tattoos and piercings are not recommended due to the risk of infection.

The topic of vaccinations and vaccination recommendations for "infection prophylaxis" will be covered in detail in the next chapter.

3.4 Vaccinations and vaccination recommendations

Due to the lifelong immunosuppression usually required by organ transplant patients, they are more vulnerable to infectious diseases. Here it is important to carefully document the vaccination status of patients **before** placing them on any transplant lists. This is to protect against infectious diseases that are preventable through vaccination, such as varicella (chickenpox) and measles. As a rule, **before** being added to a transplant list, patients should be vaccinated according to the latest version of the Swiss vaccination schedule found on the website of the Federal Office of Public Health (FOPH).

Federal Office of Public Health – Swiss vaccination schedule www.bag.admin.ch/bag/de/home/gesund-leben/gesundheitsfoerderungund-praevention/impfungen-prophylaxe/schweizerischer-impfplan.html



Missed vaccinations (primary immunizations, booster vaccinations, supplemental vaccinations for at-risk groups, including hepatitis B) are to be given promptly and documented in the vaccination record or online.

Nevertheless, a life-saving transplantation of vital organs should not be delayed due to incomplete vaccination status. A fast-track vaccination schedule for persons before they receive a solid organ transplant is available on the FOPH website. The information includes the mandatory minimum intervals in months.

After transplantation, the patient's existing vaccine protection is to be recorded and selectively recommended vaccinations given later. In these cases, the vaccine recommendations of the FOPH and Federal Commission for Vaccination (FCV) are considered standard. It should be noted that a limited immune response in the transplant patient can be expected due to the immunosuppression required after transplantation. Here, the vaccination information documented before transplantation is important. Adequate vaccine protection may need to be tested with antibody tests. During the first six months following transplantation, primary and supplementary vaccinations are usually not recommended due to diminished immunocompetence and vaccine response.

The annual seasonal flu vaccination is definitely indicated for these at-risk patients. Even as time passes after transplantation, the immunocompetence and vaccine response is usually still compromised, meaning missed vaccinations and booster vaccinations are to be given in addition to the annual seasonal influenza vaccination and pneumococcal vaccination (with 13-valent pneumococcal conjugate vaccine Prevenar13*). In addition, basic immunisation and annual boosters against SARS-CoV-2 are highly recommended.

Despite immunosuppression and the diminished vaccination response it causes, patients develop an immune response after solid organ transplantation. Vaccinations do not usually increase the risk of transplant rejection.

As a rule, the use of live vaccines after transplantation is **not** allowed, because it can lead to viral reproduction (e.g. live vaccines against varicella, measles or yellow fever). It is generally recommended to check the vaccination status of all household contacts against the Swiss vaccination schedule and to close any vaccination gaps, including the annual vaccination against seasonal influenza.

Because today's transplant patients tend to enjoy travelling, this also raises the question of which vaccinations are required when travelling to certain regions. The centres for travel medicine should be consulted in such cases. They offer special appointments to advise patients on their individual travel plans. It is imperative that patients disclose the status of their organ transplantation and current immunosuppressive therapy to the vaccination adviser at the travel medicine centre and discuss these vaccination recommendations with the attending transplant medicine specialist. A yellow fever vaccination after organ transplantation is contraindicated.

Vaccination against tick-born meningoencephalitis (TBE) is recommended in Switzerland. As for human papilloma virus (HPV), it may call for a vaccination before and, in some situations, even after the person has become sexually active.

Vaccinations are an important aspect of organ transplantation and should be checked before transplantation and completed if necessary. Live vaccines are **not** allowed for people taking immunosuppressants. The seasonal flu vaccination is essential for transplant patients and those around them.

3.5 Complications following transplantation

Life after solid organ transplantation is usually only possible if the person takes immunosuppressants for the rest of the life. This is because the human body recognizes the transplanted organ as foreign, and the immunoreaction triggered by the body would lead to an organ rejection. Immunosuppression keeps this process in check so that the transplanted organ remains functional.

What are known as T-cells, which belong to the category of white blood cells (leukocytes), play a key role in the body's immune defences. Receptors that recognize foreign substances (antigens), such as the tissue characteristics of foreign cells, are responsible for binding antigens to T-cells. In addition, the T-cell receives other signals, known as secondary signals,

from the foreign tissue via other receptors, causing T-cell activation. The T-cell then produces signalling substances that tell other immune cells to attack the foreign cells.

The cellular rejection of transplanted organs has been a well-known phenomenon for a long time, but antibody-based immunoreaction, which was hardly given much attention until a few years ago, also plays a role. Today, however, we know that humoral immunoreaction in transplant medicine plays just as much of a role. Immunosuppression counteracts this cellular and humoral activation through various mechanisms.

A distinction is generally made between an acute and chronic rejection. This failure of the transplanted organ can occur at any time after organ transplantation.

The risk of acute transplant rejection is highest during the first year following transplantation. Today, acute transplant rejection is rather unusual thanks to the use of effective immunosuppression, provided that the patient diligently and regularly takes their medications as prescribed by their physician. Through frequent testing and monitoring of the patient, the goal is to prevent an acute transplant rejection or at least identify it at an early stage and treat it immediately by temporarily increasing the dose of immunosuppressants. Transplant function is checked differently depending on the organ, among other things. These generally include lab tests, imaging and even invasive diagnostic biopsies as well as certain organ-specific tests, such as pulmonary function tests in patients who have undergone lung transplantation, which also includes daily self-monitoring by the patient at home. Chronic rejection usually develops only after the first year following transplantation and results in chronic transplant failure (CTF) with sustained loss of function. Chronic rejection remains the Achilles' heel of transplantation for all solid organs, and unfortunately it is still not adequately understood. There are many similarities between various solid organs with respect to chronic rejection, but there are also various differences. The details go beyond the brief scope of this chapter, however.

A case of chronic transplant rejection in heart transplant patients results in what is called transplant vasculopathy. A total of 50% of heart transplant patients develop transplant vasculopathy ten years after transplantation. Chronic rejection following lung transplantation is now described using the generic term chronic lung allograft dysfunction (CLAD). The most common clinical picture is bronchiolitis obliterans syndrome (BOS), where ultimately the small respiratory pathways close up due to complex multifactorial processes of connective tissue reconfiguration. BOS is diagnosed clinically on the basis of a permanent loss of lung function. Five years after transplantation, nearly 50% of all living lung-transplant patients develop CLAD. The treatment options are limited and may involve what is known as immunomodulation with the macrolide antibiotic azithromycin (Zithromax®), additional procedures such as extra-corporal photopheresis (ECP) or total lymphocytic irradiation (TLI). Fortunately, chronic rejection following liver transplantation is less common now than it was in the past. With CNI immunosuppression, the current prevalence is 5 - 15%, and less than 5% of all cases of organ loss after liver transplantation can be attributed to chronic rejection. Because advanced stages of CTF after liver transplantation can usually no longer be well controlled with immunosuppression, early detection is all the more important. Chronic rejection after kidney transplantation is caused by immunological and non-immunological factors. Irreversible restructuring processes in the transplant kidney and transplant vasculature occur here. This is referred to as chronic allograft nephropathy (CAN). Here again, early detection is important to offer patients a personalized treatment plan and to at least prevent the chronic rejection from progressing. In cases of progressive chronic rejection with increasing loss of function in the transplanted organ, re-transplantation is the last treatment option.

Because the development of chronic rejection with CTF after solid organ transplantation is still always the limiting factor for long-term survival and treatment options are unfortunately limited, the early detection and treatment of any possibly controllable risk factors is especially important.

Achieving the ideal immunosuppression after solid organ transplantation is often a difficult balance for each individual patient. Simply said, "as much as necessary, as little as possible". The goal of immunosuppression is to prevent rejection of the transplanted organ. On the other hand, excessive immunosuppression has the undesirable side effect of greater susceptibility to infection. Today, attempts are usually made to adjust immunosuppression to the individual, depending on the type of transplant, the clinical progression following transplantation, the frequency and severity of acute rejection reactions, the patient's age etc. A "one-size-fits-all" approach to immunosuppressive treatment should be avoided.

Consequently, the lifelong use of immunosuppressants can lead to the development of side effects of varying severity. One particularly serious effect of immunosuppression is an increased risk for certain types of **cancer**, for example **skin cancer**, **cervical cancer and lymph node cancer**. The precise underlying mechanisms between immunosuppression and tumorigenesis are not yet fully understood. It is known, however, that the human immune system is essentially able to identify and fight tumour cells. This mechanism appears to be compromised under immunosuppression, allowing tumour cells to more easily multiply and develop into cancer. Of the 5672 patients whose data was analysed in the STCS Annual Report 2020, 8.7% developed some type of cancer (excluding skin cancer) during the observation period, and nearly 13% developed skin cancer (median: roughly three years after transplantation). The most common type of cancer overall following organ transplantation is non-melanoma skin cancer. Its risk can be reduced considerably with proper sun protection (hat, clothing, SPF 50 sunscreen) and avoiding sun exposure. Patients are advised to regularly examine their skin themselves and see a dermatologist at least once a year for a full-body examination.

Other common side effects of immunosuppression include **high blood pressure**, which should be monitored regularly and minimized by reducing dietary salt intake. Other known side effects include **fat metabolism disorders** (high cholesterol).

3.6 Everyday life and work

Depending on the type of organ transplantation, patients can be discharged from hospital and return home a several days or weeks after transplantation or after a subsequent stay in a rehabilitation clinic. They will then begin to readjust to home life with new guidelines for patients as well as their families and close contacts. Nurse specialists, physicians and other health professionals will provide patients with detailed information for this phase, including specific bulletins, information brochures and patient training sessions.

Organ transplant patients remain under close medical observation, either directly at the transplant centre or in the care of an experienced physician specializing in transplant medicine who will work with the transplant centre in various ways. It is necessary to closely monitor the transplanted organ and its function, including looking for any side effects caused by immunosuppression, which the patient will usually take for the rest of their lives. In general, an all-around healthy lifestyle is recommended.

Medical check-ups will be more frequent during the first weeks up to the 12th month after transplantation. The more time that has passed since the patient's transplantation, the fewer check-up appointments will be needed at the transplant centre unless a chronic rejection reaction with CTF or other medical problems occur. The attending transplant team includes doctors experienced in transplant medicine as well as specialized nurse specialists. Depending on the transplanted organ, check-up examinations (surveillance) will be carried out to a varying extent. These sometimes also require invasive testing by taking a biopsy, for example from the transplanted heart (endomyocardial biopsies) or the transplanted lung (transbronchial biopsy) or the transplanted kidney (ultrasound-controlled kidney transplant biopsy). The purpose is for the pathologist to rule out the possibility of a transplant rejection. These surveillance examinations help to control immunosuppression for the individual patient. Depending on the transplanted organ, patients are also instructed to monitor their own health status from home (patient self-management) and communicate any changes to the attending physician or transplant team. Sometimes self-management from home also includes testing performed by patients on their own with instruments. These range from any indicated blood pressure measurements to daily lung function tests with a hand-held micro spirometer. The test values are recorded by the patient and discussed during the medical check-up. The values can be recorded in a journal, or many patients, especially young ones, now like to use special apps on their smartphones for this. If the patient notices changes in self-measured values, they are advised to immediately report them to the treatment team. The electronic patient dossier can facilitate the exchange of information between the various specialists. In addition, patients are educated about regularly taking medication as well as any side effects of medication and possible symptoms of illness they should look for in particular (nausea, vomiting, diarrhoea or constipation; headache, sore throat and joint pain; cold symptoms; red, swollen or painful areas on the body; skin changes; fever). If the patient is experiencing these symptoms, they should not wait until their next examination and should immediately contact the transplant centre or their specialist. At many transplant centres, patients can practice taking their medication before leaving the hospital.

Patients usually also receive nutritional advice about a well-balanced, moderate diet with plenty of daily variety as well as interactions between certain foods and medications. One typical example is grapefruit juice, which should not be consumed when taking immuno-suppressants. Transplant patients should always ensure appropriate food hygiene when selecting and preparing foods. Excessive alcohol consumption should be avoided.

Fundamentally, the goal of organ transplantation is not only to prolong the patient's life but also to improve their quality of everyday life. This also includes starting or resuming work following transplantation. The (re)integration into working life is generally encouraged; regular or even part-time work gives structure to a person's daily routine and fosters social contacts outside of a person's own household and circle of friends and family. Starting work should be discussed with the attending physician. The transplant teams will advise patients and also bring in social workers if needed. Additional assistance is offered in navigating regulations relating to invalidity insurance. In some cases, such as after lung transplantation, it is also advisable to discuss the choice of work with the attending physician.

The time on the waiting list, the hospital stay and the return to everyday life can cause questions and worries to arise. For certain patients, psychological help may be necessary.

3.7 Sport and sexuality

Sport

As a rule, plenty of exercise and participation in sports are a rewarding goal after a successful solid organ transplantation. However, athletic activities must be adjusted to the person's individual health status and fitness level. The goal is to strengthen muscles and improve endurance. It is important for patients to begin mobilisation exercises soon after transplantation as directed by their physician and to resume with their daily physical activities in a timely manner. After transplantation, certain patients will remain very limited, and a stay at a rehabilitation clinic is advisable after consulting with the transplant team.

Depending on the type of transplantation, certain sports, such as contact sports and martial arts, are to be avoided for the first three months after transplantation. Ideally, no loads over 2.5 kg should be lifted during the first six weeks and no loads over 5 kg in the first 3 months either. We recommend consulting the transplant team about this. Endurance sports like jogging or cycling are particularly suitable for many patients. For the first three months after the transplantation, patients are recommended not to take exercise beyond using a stationary bike at home with low resistance. At some centres, lung transplant patients are advised to avoid swimming for the first few months after transplantation and then generally to swim in natural bodies of water. Here it is also a good idea to consult with the transplant team. Sports are also popular among organ-transplant patients and not only have a positive impact on both the body and the mind. Most people who exercise regularly feel more balanced and emotionally resilient. Physical activity helps to better manage the stresses of everyday life. Depending on the type of organ transplantation, medical training therapy (MTT) is often already started at the transplant centres under the professional direction of physiotherapists. It involves targeted strength, endurance, mobility and coordination training of the patient's musculoskeletal system and cardiovascular system. MTT has a primarily medical focus, meaning that it is not fitness training in the conventional sense. MTT combines exercise and training principles with the insights from the field of pathology. In other words, regular MTT supports the rehabilitation process following organ transplantation. Through targeted training in the areas of endurance, mobility, coordination and strength, the goal is to improve resilience of the musculoskeletal system and cardiovascular system and thus improve performance in the patient's everyday work and leisure time. MTT is prescribed by a physician, which means patients are advised to talk to their attending transplant medicine physician.

Sexuality

In general, persons can engage in sexual activity again after transplantation. This is important, because a fulfilling love life is generally conducive to overall satisfaction in life. Patients who are waiting for an organ transplant must often put up with problems in their sex lives due to their constant poor health condition. Many transplant patients are able to regain a normal sex life, however. Certain medications (e.g. drugs used to lower blood pressure) may affect the person's sexual activity (difficulties getting an erection, loss of libido). If the patient is non-monogamous, it is important for them to prevent sexually transmitted diseases, for example, by using barrier protection (condoms). Reliable contraception after transplantation should be discussed with an experienced gynaecologist. As a rule, transplant patients do not have to give up on having their own children. Female organ transplant patients should **always** discuss any plans to have children with the transplant team and an experienced gynaecologist at an **early stage.** During the first year following transplantation, pregnancy should be avoided due to the heavy doses of immunosuppressants.

The possible risks associated with pregnancy (increased risk of infection, adjusting immunosuppression, increased risk of foetal deformities, risk of expulsion, prematurity) should ideally be discussed fully before conception. Men who have received organ transplants should also consult with the transplant team before conceiving children.

3.8 Travel following transplantation

Through good preparation, it is generally possible to travel again after organ transplantation – with certain limitations. Before travelling it is crucial that the transplant patient is in good health and that the transplanted organ is stable and functioning. In general, these criteria are met a year after transplantation. It is always advisable to discuss the desired travel plans with the attending physician or transplant team in due time – ideally three months before the planned trip.

Before travelling

Basically, it is important for transplant patients to select an appropriate travel destination (climate, standard of hygiene). When planning to travel by plane, it may be necessary for a physician to assess the patient's fitness to fly. The completeness of travel documents, travel cancellation insurance, and arrangements for return travel in case of an emergency need to be clarified in detail. Travel documents from the transplant centre should ideally be in English. Taking medications (immunosuppressants) in relation to time zone changes and medication reserves need to be discussed at an early stage with the transplant team, which will be glad to advise the patient. Everything relating to vaccinations has already been discussed in this document. Completing the "Before travelling" checklist is recommended (see Table 1).

Travel following transplantation requires detailed planning and good preparation, which should normally begin three months before leaving for the trip, particularly in the case of long-distance travel. The attending physician should be consulted or the transplant team notified in due time. Travel medicine centres offer additional advice in specific matters relating to the destination.

Table 1 "Before travelling" checklist

Destination

- Timely consultation with transplant specialist (3 months ahead)
- □ Appointments for routine examination
- Travel advice at centre for travel medicine (optional depending on the country of travel)
- □ Appointment with your doctor for post-trip examination

Insurance policies

- □ Adequate insurance protection for international travel (health insurance, cancellation insurance)
- □ Insurance for return transport in an emergency

Travel documents and medical documents

- □ Valid passport, visa (if required)
- Customs letter: certificate for carrying all medications
- Patient passport with important contact details for wallet
- Diagnostic list (in English)/current laboratory results
- □ Medications list and schedule
- □ Prescription
- Current international immunization card
- □ Allergy card
- Medical contact in country of travel (24-hour service)
- Copies of all personal documents (travel tickets, passport, health insurance, insurance documents, credit cards etc.) and current medical documents

Long-term medications

- Note time differences find out from your transplant specialist if you need to consider the time difference when taking your medications
- □ Transport of long-term medications: Enough for at least 7 days in carry-on luggage, rest in the suitcase (For flights longer than four hours, medications should be transported in hand luggage, as the luggage compartment is too cold. If possible, divide medications up between several items of luggage (accompanying person)).

Travel and emergency first-aid kit

- Additional medications, emergency medication and travel first-aid kit (in consultation with your doctor)
- □ Thrombosis prevention (in consultation with your doctor)
- □ Thermometer
- □ Condoms

Vaccinations

□ Check vaccination status, booster vaccinations and infection prophylactics (in consultation with your doctor) – at least 3 months before travelling

Sun protection

- □ Sun protection with high sun protection factor (SPF 50)
- Head covering and long clothing, ideally protecting against UV
- Sunglasses

Insect protection

- □ Insect repellent for skin and textiles
- Clothing with long sleeves, long trousers
- Mosquito netting

Hygiene

- □ Hand disinfectant (not more than 100 ml in carry-on baggage)
- □ Face mask (in consultation with your doctor)

During the trip

To prepare for risk situations and potential complications during the trip, **before** travelling, transplant patients should talk to the transplant team about what to do if they fall ill/have an emergency, e.g. if they experience diarrhoea. Many complications can be avoided by strictly observing hygiene guidelines for food and drinking water. A simple (but reliable) rule of thumb is, "**boil it, cook it, peel it or forget it**". Guidelines for swimming should be followed as well, because immunosuppression makes transplant patients more vulnerable to infections. For example, swimming and diving in tropical freshwater is to be avoided. Swimming in bodies of water that have been officially designated as safe is recommended. Wearing sandals or beach/swimming footwear is recommended to protect feet against injury (broken shells) or infections (fungal infections of the feet, foot warts). As a rule, direct contact with animals should be avoided. Always consult a physician after an animal bite due to the risk of infection. Insect repellent and mosquito netting are to be used.

After the trip

A post-trip examination at the transplant centre should be made **before** leaving for the trip. If new symptoms occur – even several weeks – after returning from the trip, the attending physician should be consulted immediately.

Travel guide – travel and holiday planning after organ transplantation www.swisstransplant.org/fileadmin/user_upload/Swisstransplant/ Publikationen/Reisehandbuch.pdf



3.9 Quality of life following transplantation

As already discussed several times, the goal of organ transplantation is not only to prolong life but, just as importantly, to improve quality of life, which is greatly diminished for patients for however long they have been waiting for a donor organ. After organ transplantation, people want to get back to their normal lives, whatever that happens to mean for the individual. Just like people who have not undergone organ transplantation, transplant patients also want to spend their time on the things in life that are important to them without being physically limited: partners, family, friends, work colleagues, social contacts and leading an independent, **self-determined life.** Transplant recipients often speak of a "second life" made possible by the transplant. They want to live mindfully, often more so and with greater self-awareness than before their transplantation.

After transplantation, people do not, of course, live fully free. They require regular medical examinations, must painstakingly take their (immunosuppressive) medications every day, may develop medical complications due to taking immunosuppressants, and live in fear that their own body may one day reject their new transplanted organ. Despite these limitations and some of these fears as well, most people feel better after than before transplantation. Many say they would opt for transplantation again and do not regret their original decision to undergo transplant surgery. This attitude towards transplantation has been documented in scientific studies.

Transplant patients usually experience a **higher** quality of life after organ transplantation, and the **positive attitude** affects many different aspects of everyday life: physical performance, emotional well-being, mental fitness, social life.

The overall positive attitude of transplant patients towards organ transplantation has also been documented scientifically in Switzerland, including in a national Swiss study. The study confirmed the generally positive attitude of the respondents towards transplantation as well as towards taking their medication and how they saw themselves. However, both patients and their life partners reported negative opinions about transplantation in terms of stress and anxiety. Patients described increased emotional stress brought on by the organ transplantation and described how they perceived their fate as more negative than did their life partners. For this reason, the perceptions of transplant patients and their life partners surrounding organ transplantation must be taken into consideration.

As described previously in detail, quality of life includes aspects of a person's normal, everyday life after transplantation, meaning a successful (re)integration into work life, plenty of exercise and sports that are enjoyable, a fulfilling sex life, and the opportunity to travel safely after transplantation. Finally, many readers wonder what thoughts are going through the mind of a person who is waiting with big hopes for a donor organ. What is the background behind the transplant? And what is life after organ transplantation like? People's lives – even after organ transplantation – have all kinds of stories to tell that are rich and varied as life itself. Some brief stories from organ transplant patients can be found on the Swisstransplant website.

Brief stories of organ transplant patients www.swisstransplant.org/de/infos-material/erklaervideos/



Authors

Version 1.0

Working Group (in alphabetical order)

- Prof Christian Benden MD
- PD Franz Immer MD

Expert Group (in alphabetical order)

- Dr Isabelle Binet MD
- Ramona Odermatt
- Marian Struker

Further reading (chronological)

Federal Act of 8 October 2004 on the Transplantation of Organs, Tissues and Cells (Swiss Transplantation Act). SR 810.2 (status as of 1 July 2007)

Federal Ordinance of 16 March 2007 on the Transplantation of Human Organs, Tissues and Cells (Swiss Transplantation Ordinance). SR 810.211 (status as of 1 January 2013)

The Swiss Federal Office of Public Health (FOPH): A Review of the Long History of Transplant Medicine. www.bag.admin.ch/bag/de/home/medizin-und-forschung/transplantationsmedizin/ transplantieren-von-organen-geweben-Zellen/geschichte-der-transplantation.html

M.T. Koller, C. van Delden, N.J. Müller, et al. Design and methodology of the Swiss Transplant Cohort Study (STCS): a comprehensive prospective nationwide long-term follow-up cohort. European Journal of Epidemiology. 2013. 28: 347 – 355

STCS. Swiss Transplant Cohort Study Report (May 2008 – December 2018). July 2019. www.stcs.ch/internal/reports/2019july-stcs_annual_report.pdf

A. Rana, E.L. Godfrey. Outcomes in solid-organ transplantation: success and stagnation. Texas Heart Institute Journal. 2019. 46: 75 – 76

R. Kumar, M.G. Ison. Opportunistic infections in transplant patients. Infectious Disease Clinics of North America. 2019. 33: 1143 – 1157

M. Slifkin, S. Doron, D.R. Snydman. Viral prophylaxis in organ transplant patients. Drugs. 2004. 64: 2763 – 2792

H. Suhling, J. Gottlieb, C. Bara, et al. Chronic rejection: differences and similarities in various solid organ transplants. Internist. 2016. 57: 25 – 37

Travel guide. Travel and holiday planning after organ transplantation. www.swisstransplant. org/fileadmin/user_upload/Swisstransplant/Publikationen/Reisehandbuch.pdf

S. De Geest, H. Burkhalter, L. Barben, et al. The Swiss Transplant Cohort Study's framework for assessing lifelong psychosocial factors in solid-organ transplants. Progress in Transplantation. 2013. 23: 235 – 246

L. Goetzmann, U. Scholz, R. Dux, et al. Attitudes towards transplantation and medication among 121 heart, lung, liver and kidney recipients and their spouses. Swiss Medical Weekly. 2012. 142: w13595

Changes

| Date | Version | Changes |
|---------------|---------|-------------|
| February 2023 | 1.1 | Corrections |

Swisstransplant

Effingerstrasse 1 3008 Bern T: +41 58 123 80 00

info@swisstransplant.org www.swisstransplant.org

