

Being related

to a transplant recipient

Preface

Now it has happened. The transplant has been completed, and the next step awaits. An exciting path is ahead as a loved one to someone who has undergone transplantation. Together, you will find the new normal. Allow it to take some time.

As a partner, family member, or close friend, you have been there for a while. During the illness, the evaluation for transplantation, and while waiting for the needed organ. Perhaps you have listened, comforted, cared for, looked after the children, the household, the practical matters, and provided support in many different ways. And maybe you have grown tired many times. Tired of how the majority of your life has been influenced by the illness your loved one has had. Tired of the time it takes for the organ to arrive and the need to put life on hold.

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These materials were developed under a healthcare collaboration between the European Society for Organ Transplantation (ESOT) and Takeda that aims to benefit patient care.



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Adapting to the new life

Following an organ transplant, life must be adapted to the new situation with a transplanted organ. Your life as a loved one is also affected.

The transplant recipient enters a new situation with hopefully better health, but with life-long medication and frequent visits to the transplant clinic. The highest number of visits is usually made during the first year, depending on the organ in question.¹

1. Unterman et al. A Descriptive Analysis of 1251 Solid Organ Transplant Visits to the Emergency Department. Western Journal of Emergency Medicine. Volume 10, Issue 1.

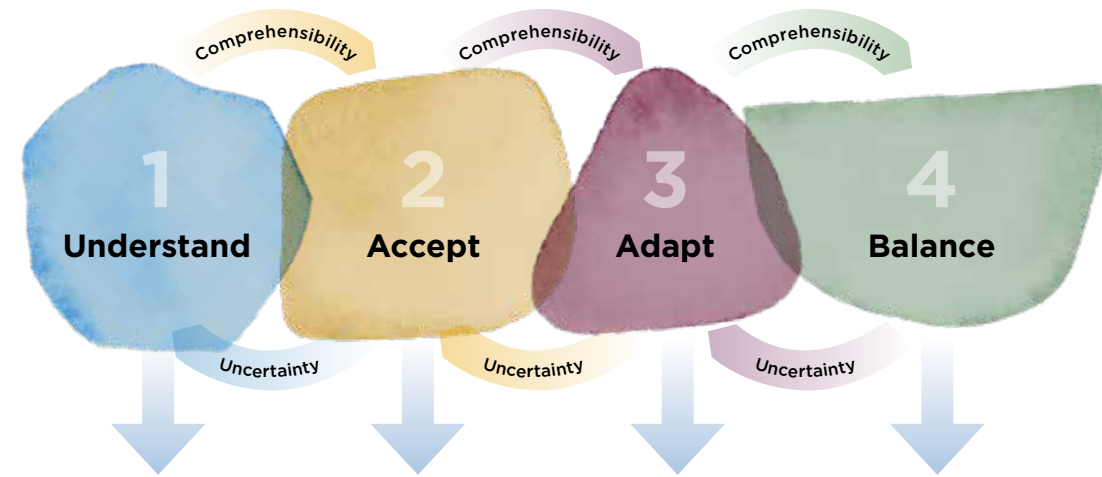
Your transplanted loved one must adjust to their new body and health, new routines and medications, exercise and social relationships, and, most importantly, the increased risk of infection due to a weakened immune system. And you need to consider that they are susceptible to infections and the various components involved in the rehabilitation process.

Depending on which organ was transplanted, it can take several months to a year before your transplanted loved one can return to work or study. Some spouses worry a lot about finances during a prolonged sick leave. When the first year as a transplant recipient has passed, you might start considering international travel, which raises new questions that you need to address together.

A common process in different phases

The process of adapting to the new normal after a transplant in the family is divided into phases. This continues as long as the transplanted organ is functional.

The goal of adaptation is for you to find a new normal and a functioning everyday life where you are able to belong to the social circle you desire, such as family, friends, work, studies, or patient associations. On the right, you can see a rough representation of the phases that both you and the transplant recipient will go through.



To be a part of a social circle and have a functioning daily life

Understanding moves you forward in the process, whereas uncertainty moves you back.

To understand what you have been through

Adaptation always starts with you and your transplanted loved one working together to understand what you have been through and what you need to do to move forward, have a functioning everyday life, and a functioning life after the transplant.

Many relatives, usually a partner, describe the entire sequence of events as more or less surreal. From the time your loved one received the call that there was a suitable organ to the time you saw your relative in intensive care or the care ward. It was simply a matter of going along with what was happening, like a bystander.

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Being able to support even when you are tired

The journey to recovery begins when the transplant recipient returns home. You want to be there, understand what's happening, and support, but you're not sure how. Or you feel like you put in so much energy and support before the transplant that it's difficult to recharge. Maybe you feel angry and frustrated about the whole situation. Perhaps you are the sole caretaker of any children, pets, or household. Life continues, around the clock, even though a transplantation has taken place.



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To accept that life has changed and live in the present

When you have reached a level of understanding about what is expected of you and your loved ones, you enter the next phase, which is acceptance.

You need to find a way to accept that the time before the transplantation was as it was, and now life post-transplant needs new routines and medications. Sometimes it's good to take it one day at a time and gradually get used to the new reality.

To feel good in the soul

Following the transplant, it is common to think, "How long will the new organ last?" This is a deeply existential question that deals with life and how long one will be given a chance to live. Existential questions are never easy to answer. They are also difficult to ask because they are associated with fear.

The transplant recipients often keep these thoughts to themselves in order not to burden those close to them. The question of how long one can live is frequently linked to a strong fear of death, but also to uncertainty. You are afraid of asking the question because you are afraid of the answer. Nonetheless, you can only find the courage to live if you dare to put your fears into words.

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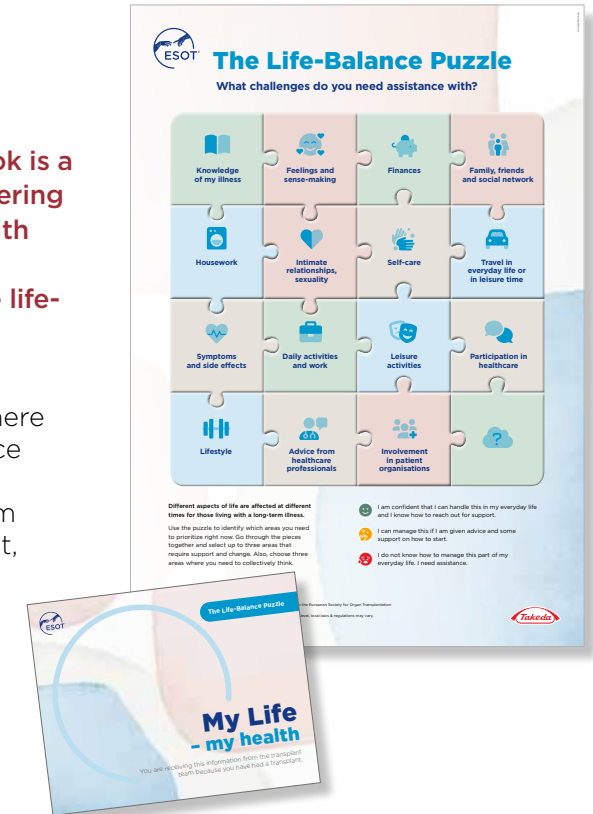
Adaptation

When you start to get a handle on the acceptance part, you'll be able to move on to the next phase. It is about the practical adjustment and management of your shared everyday life.

This is how you use the life-balance puzzle

The "Life-Balance Puzzle" workbook is a tool for adapting to life and discovering the new normal. Before meeting with the nurse or doctor, you and your transplanted loved one can use the life-balance puzzle together.

- You discuss whether there are any aspects in your daily life where you require healthcare assistance with the help of the material. Your loved one may benefit from seeing an occupational therapist, counsellor, or psychologist.

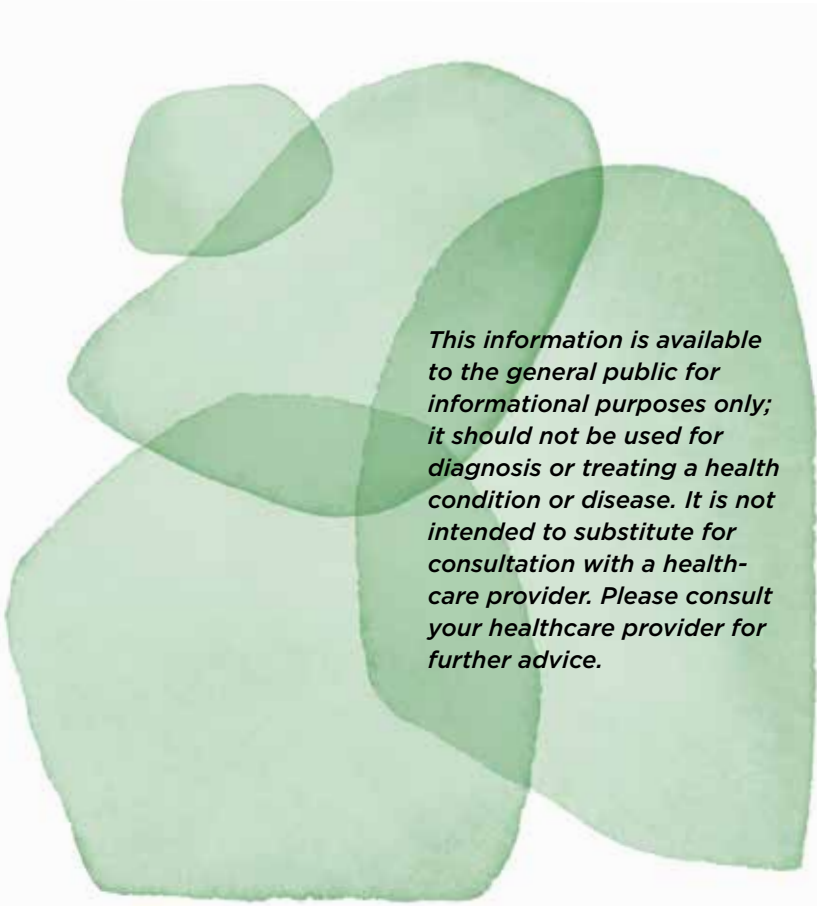




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Balance

After determining what needs to be adjusted in the post-transplant phase, the final phase focuses on balance. The transplant recipient goes about his or her daily life with a functioning organ and finds a sense of balance. The new has become normal. The balancing act continues throughout life so that your loved one can be in the community where they want to be and feel connected.



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Even you need balance in your life

When the transplant recipient starts to feel stable and manage their daily life, it is not uncommon for a relative to feel bad, especially mentally. Then there is suddenly space for you to feel your own tiredness, your own worries, your sadness that everything has been so difficult at times, and the weight of responsibility for everything that the transplant recipient has been unable to cope with.

Now is the time to rest, take care of yourself, begin exercising, let go of any sadness, reconnect with friends, and possibly return to work or increase your working hours. It's no surprise you're tired. It's also okay for you to feel sad about the tough times. The important thing is that you find a way to move forward and find your own balance. If you find it difficult to do it on your own, ask for help at your health center.

To avoid infection

The risk of infection is greatest in the first six months after the transplant.¹

There are many ways to protect the recipient. The best way is to wash your hands with soap and water. Your transplanted loved one should not isolate him or herself, but should be careful during the first three months. Think about what is reasonable.

Lung transplant recipients must be careful and protect themselves against infections for six months.²

If there are signs of symptoms, it is critical that the transplant recipient contact their clinic and explain how they are feeling so that an assessment can be made as to whether antibiotics or other treatment is required.

Signs of infection¹

- **General malaise.**
- **38 degree fever or higher.** For lung transplant recipients, 37.5 degrees applies.
- **New pains** in the body or in the joints.
- **Vomiting or diarrhoea** that makes it difficult to keep down medicines, liquids, or food.
- **Flu-like symptoms** such as coughing, body aches, shivers, or chills.
- **Sore throat, cold, runny nose or shortness of breath.**
- **New fluid from the wound,** which is red and irritated. Comes from pus and smells bad. Is sore and swollen around the surgical wound.
- **Urine burning** may indicate a urinary tract infection.

1. Winterbottom F, Jenkins M. Infections in the Intensive Care Unit. Post transplant Infections. Review. Crit Care Nurs Clin North Am. 2017 Mar; 29(1): 97-110). Doi:10.1016/j.cnc.2016.09.002 2. Magda G. Opportunistic Infections Post-Lung Transplantation: Viral, Fungal, and Myobacterial. Clin Chest Med. 2023 Mar;44(1): 159-177. Review

1. • Infection in Organ Transplantation Am Journal of Transplantation 2017
• Infection in solid Organ NEJM 2017
• Urinary tract infections in solid organ transplant recipients: Guidelines from the American Society of Transplantation Infectious Diseases Community of Practice - (link to the abstract - <https://onlinelibrary.wiley.com/doi/epdf/10.1111/ctr.13507>)

The goal is quality of life

One of the most important goals of a transplant recipient, regardless of organ, is quality of life.

The aim of transplantation is to improve quality of life. Daring to live as an organ recipient is the first step towards discovering the quality of the new life!

The transplant outpatient clinic will provide your transplanted loved one with written information about lifestyle changes and health recommendations.



Esot.org

Visit esot.org to learn more about what it's like to live as a transplant recipient, expand your knowledge, and find contact information for patient organisations and other resources.



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These materials have been reviewed and approved on an international level, local laws & regulations may vary.

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