



My Life - my health

You are receiving this information from the transplant team because you are a transplant recipient.

Preface

The transplant is now complete. Every day is a step forward, and today marks the beginning of the rest of your life. The goal is for you as a transplant recipient to feel seen and validated as the person you are.

Receiving an organ means facing significant and usually positive challenges such as regaining health, returning to work or studies, and being able to resume one's social relationships and leisure interests.¹

To be able to feel good, have strength, and cope without being as reliant on healthcare or other people as before. At the core, there may be a certain melancholy associated with having been critically ill, but also with being a recipient of an organ that someone has donated. But life goes on.

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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.

1. Yang et al. Liver transplantation: a systematic review of long-term quality of life. *Liver Int.* 2014 Oct;34(9):1298-313. doi: 10.1111/liv.12553. Epub 2014 Apr 23.

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A transplant for life

Undergoing a transplant affects your entire life. A great deal of thoughts and feelings arise. It is stressful, and life is frequently put on hold while awaiting an organ. When the transplant is completed, both you and others expect you to recover and return to your normal life.

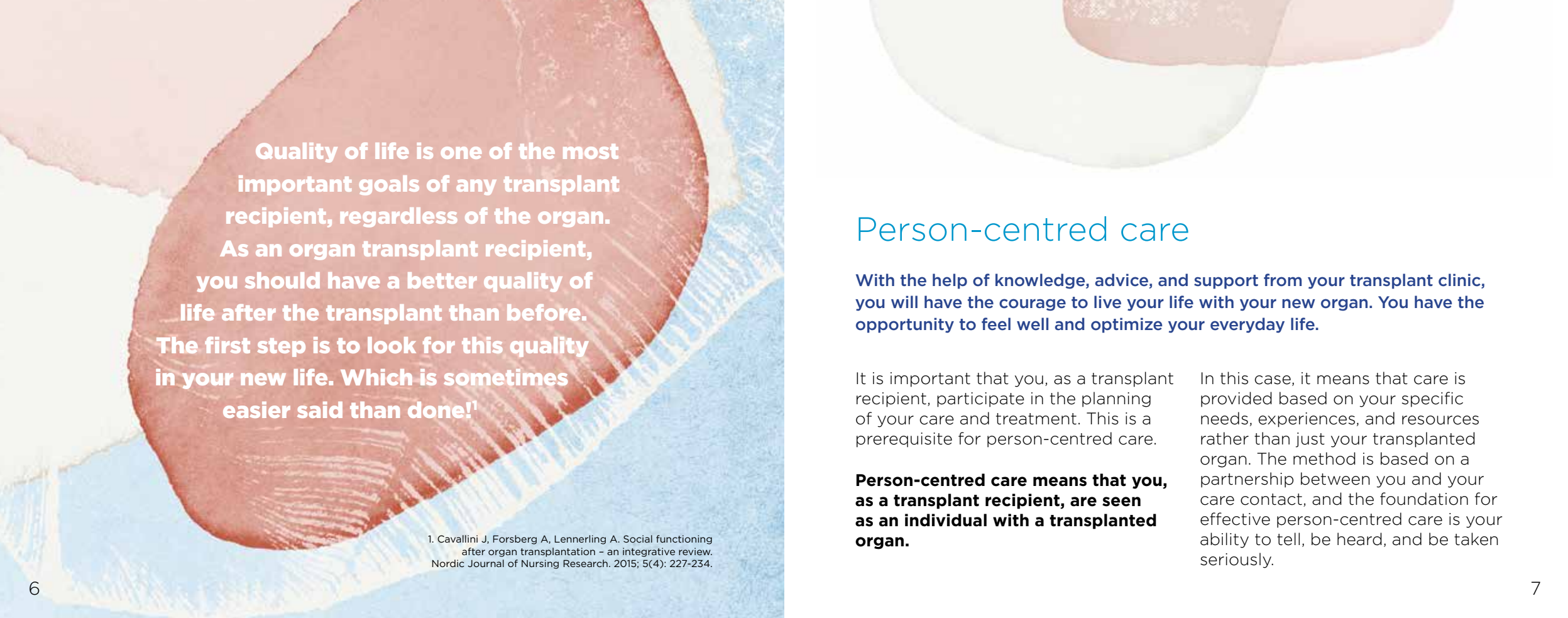
Emotions go up and down. Intense joy can suddenly turn to tears and frustration. You don't always recognise yourself.

“You can find courage when you put your fears into words!”

One of the most common questions after a transplant is: “How long will the new organ last?”

It's a deeply existential question about your life. Existential questions are never easy to answer. They are also difficult to ask because they are associated with fear.

For example, the question of how long I will live is frequently associated with a strong fear of death, but also with uncertainty. I'm afraid to ask the question because I'm afraid of the answer. However, only by daring to put your fears into words will you be able to find the courage to live!



Quality of life is one of the most important goals of any transplant recipient, regardless of the organ. As an organ transplant recipient, you should have a better quality of life after the transplant than before. The first step is to look for this quality in your new life. Which is sometimes easier said than done!

1. Cavallini J, Forsberg A, Lennerling A. Social functioning after organ transplantation – an integrative review. *Nordic Journal of Nursing Research*. 2015; 5(4): 227-234.

Person-centred care

With the help of knowledge, advice, and support from your transplant clinic, you will have the courage to live your life with your new organ. You have the opportunity to feel well and optimize your everyday life.

It is important that you, as a transplant recipient, participate in the planning of your care and treatment. This is a prerequisite for person-centred care.

Person-centred care means that you, as a transplant recipient, are seen as an individual with a transplanted organ.

In this case, it means that care is provided based on your specific needs, experiences, and resources rather than just your transplanted organ. The method is based on a partnership between you and your care contact, and the foundation for effective person-centred care is your ability to tell, be heard, and be taken seriously.

To be taken seriously as a transplant recipient

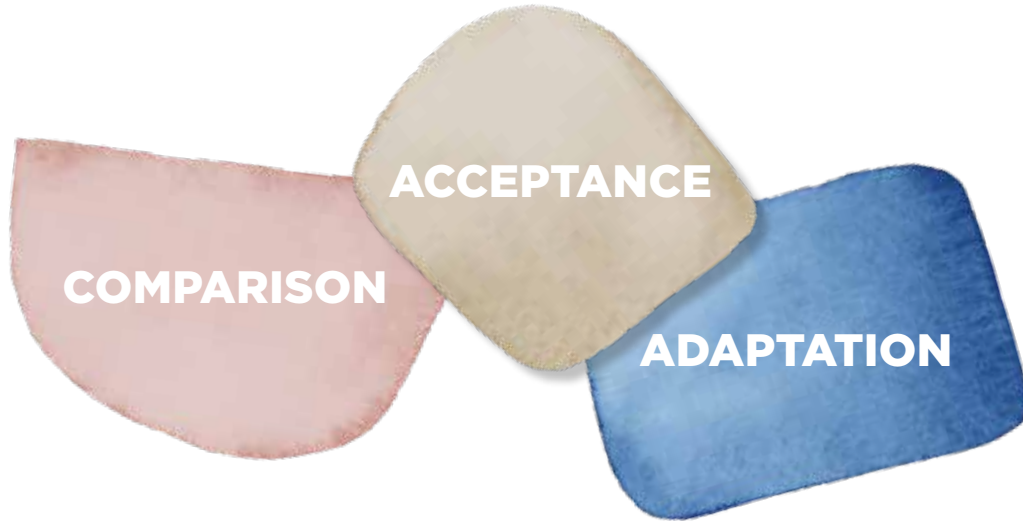
Person-centredness is based on you being taken seriously in healthcare. According to the research, the most important aspects of being taken seriously are:

- **You are listened to.**
You get to tell your story, and the staff listen to you.
- **You will receive assistance in understanding what will happen next.**
Together with nurses or doctors, you will create a care plan.
- **You will receive assistance in understanding what has happened.**
Sharing and receiving feedback about your experiences provides a sense of coherence.
- **Your concerns are taken seriously.**
Your experience and suffering will be validated.

- **Your symptoms are taken seriously.**
Your symptoms and challenges are documented by nurses and/or doctors. You develop a strategy for dealing with them together, and you investigate whether there are any difficulties in dealing with them.
- **You are taken seriously as a person.**
You are capable of improving and caring for your health. We want to work together to help you find the resources you need.
- **You are currently feeling good.**
There will be times when you feel great and times when you feel terrible. Time is allocated during the initial visits at the clinic to discuss these matters.
- **You feel safe**
You have regular contact with a nurse and/or doctor.

The foundations of rehabilitation

Three specific strategies are required for you to rehabilitate and adjust to life as a transplant recipient and find your new normal:¹



1. Lundmark M, Lennerling A, Forsberg A. Developing a Grounded Theory on Adaptation after Lung Transplantation from Intermediate-term Patient Experiences. *Progress in Transplantation* 2019. Jun; 29(2): 135-143.



Comparing is a good way to progress in your rehabilitation. Transplant recipients frequently compare how they felt before the transplant to how they felt immediately after the transplant.

Setting goals and tracking your progress will reassure you that you are on your way to finding your new normal. Let it take time.

Tools you can use together with your nurse or doctor:

One **life-balance puzzle** and one **workbook** for dealing with everyday life and life in general. You discuss whether there are any areas where you require healthcare assistance with the help of the material. It may be necessary to consult with an occupational therapist, counsellor, or psychologist.

■ This is how I want to feel

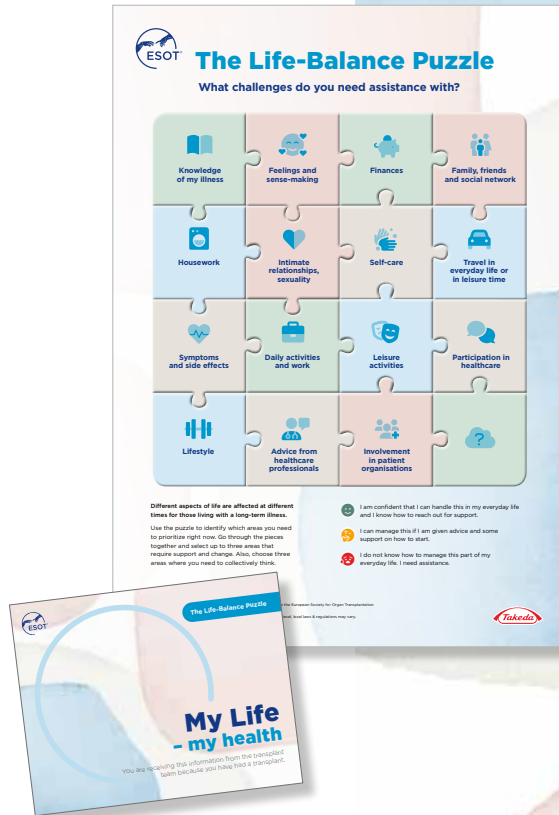
- my health goals

■ This is something I can do on my own

- utilizing my own resources

■ This is something I need assistance with

- my challenges



ACCEPTANCE

Only after you accept that the transplant has been completed can you begin to adjust your life and daily routines in order to find your new normal. Acceptance occurs when you believe you have the necessary conditions and resources to live a normal life with your new organ.

An inventory and analysis of your personal resources is required to achieve acceptance. You will be asked to complete various assessment instruments with your care contact as part of the inventory. These allow you to see what physical, mental, social, spiritual, and financial conditions you need to live a normal life. The goal is for you to feel as good as possible.

ADAPTATION

An organ transplant recipient may require some processing and a lifelong adaptation to daily life. Frustration, obstacles, and other perceived barriers can all obstruct successful processing.

It is important that you inform the medical staff at your transplant clinic about your difficulties so that they can point out opportunities and provide assistance.

Not only must you adapt to your surroundings, but your surroundings must also adapt to your conditions. This means that your family members, as well as your workplace and employer, may need to adapt. Your loved ones may require more information about organ transplantation and how it affects you because you may live together and everyone is affected if someone has a change in their health status.

Obstacles and difficulties are listed based on what you can do yourself, what the care can assist you with, and which possible strategies need to be developed or revised to manage daily life as a transplant recipient.

Many people feel healthier when they can work or study!¹ The care must support you so that you can work/study in whole or in part.

Important efforts include educating the employer and colleagues, and working to adapt the work situation. Not all transplant recipients require this, but it may be provided to you if necessary.

1. Cavallini J, Forsberg A, Lennerling A. Social functioning after organ transplantation - an integrative review. *Nordic Journal of Nursing Research*. 2015; 5(4): 227-234.

Important keys to an improved health and functioning everyday life

There are four essential keys to an improved everyday life as a transplant recipient. These are largely reinforced by the healthcare staff's assistance.

Trust

Trust in care occurs when you are treated as a person rather than a patient dependent solely on your transplanted organ. That someone sees you all.

A stable and continuous care relationship with your care provider builds trust. Your carer serves as an anchor, contact centre, and coach. She/He encourages you to persevere and manage the life-long treatment.

Security

Security is about your belief in yourself, your ability to manage your life, and what is required when you are an organ recipient. One of the most important aspects of feeling secure is that your possible uncertainty is reduced and your readiness to act is strengthened.



Patience

Adapting to life as a transplant recipient takes time and patience. Setting realistic goals and evaluating them in stages can help. Care is there to support and encourage you when your patience runs out.

Strength

Living with a transplanted organ requires strength. Discuss any treatment side effects and focus on the positive effects. For those who work, it is important that you can do your job, at least partially, despite your medication's symptoms and side effects. Care can assist you in responding to and dealing with possible ignorance and questions of those around you. A visit to a psychologist can provide you with mental strategies that will help you. A good strategy is to simply take one day at a time. If you need assistance in informing your employer, talk to your healthcare provider.

Revisit the transplant clinic

It is best if you are prepared before the visit so that the meeting with the care can be focused on you as a person and your needs. You can use this checklist as a starting point for thinking about your situation.

- **How are your self-checks going?**
Something not as expected?
Temperature, weight, blood pressure, and spirometry results (for lung transplant recipients).
- **How can medication be taken?**
Do you take medication at set times?
Do you remember to renew your prescriptions?
Don't forget to pick up your prescriptions on time.
- **Do you have any signs of infection?**
Cough, runny nose, fever, shortness of breath, burning when urinating, diarrhoea, or sores are all signs of infection.
- **Do you have any symptoms that you are concerned about?**
Symptoms may include, for example, nausea, trembling hands, pain in the hands or feet, severe fatigue, or shortness of breath.

- **Do you need advice on how to eat well?**
Consider how you eat.
- **Do you need advice on exercise and physical activity?**
Consider how active you have been recently.
- **Of course, you don't smoke!**
If you happen to do so, seek help for smoking cessation!
- **Do you have questions about alcohol?**
Discuss with your doctor or nurse what applies to you.
- **Do you need to practise how to protect yourself from the sun?**
It is especially important to protect yourself from the sun from April to September.
- **How are you mentally?**
Think about how you have been feeling lately. Upset? Depressed? Worried?

Write down your thoughts and bring them to the meeting. You can use the life-balance puzzle to circle which aspects of your daily life you need to improve in order to feel good.

- **How does your typical day go?**
Questions or concerns?
Are you settling into routines after the transplant? Is it time to return to work or study?
Are you planning to travel and need to be vaccinated? Sex? Sports and leisure activities?



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.



This information is available to the general public for informational purposes only; it should not be used for diagnosis or treating a health condition or disease. It is not intended to substitute for consultation with a healthcare provider. Please consult your healthcare provider for further advice.

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

C-ANPROM/EUC/CORP/0031 Date of Preparation: November 2023

