

What does it mean to be a transplant recipient?

Show that you understand how a transplant affects a person's entire life, and that you take the person seriously.

- Being a transplant recipient is a **long-term condition**. It means transitioning from a serious or life-threatening disease to a life of better health, but with lifelong medication.
- **Taking immunosuppressive medication for the rest of your life** or as long as you have your transplant (in the case of a kidney) may require changing your way of life.
- Because of immunosuppressive medication, **transplant recipients are susceptible to infections**. When the immune system is suppressed, symptoms and side effects that are unusual and difficult to manage on your own may occur.
- Being a transplant recipient means **living with a potential risk of organ rejection**. Some transplant recipients live in constant fear that this will happen.
- Many transplant recipients are **concerned about how long their transplant will last**, which can lead to stress and illness.
- Transplant recipients receive numerous advice and recommendations on how they **need to modify their daily lives** for the functioning of the transplanted organ and their life as a transplant recipient. **It can be challenging for the individual undergoing transplantation**. You may need to support both the learning process and lifestyle changes to facilitate a successful adaptation to daily life.



Photo: Shutterstock

“I sit here wondering how long it will last.”



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.

Guidance and collaboration

The transplant recipient requires guidance in dealing with the society's questions about the transplant, as well as ignorance or prejudice. Educating employees at a workplace meeting or informing employers can be extremely beneficial. A psychologist's mental strategies can also help to strengthen the person.

Rehabilitation can be successful if the entire care team collaborates around the transplant recipient's situation. According to the research¹, occupational therapists and psychologists play important roles. A stable and long-term care relationship with a doctor and a nurse is also important.

¹ Lundmark M, Erlandsson L-K, Lennerling A, Almgren M, Forsberg A. Health transition after lung transplantation. Journal of Clinical Nursing. 2016 Aug; 25 (15-16):2285-2294.



The people in the pictures have nothing to do with the context.

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

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Person-centered care for transplant recipients



This is a guide to person-centered care that focuses on the individual's life as a transplant recipient.

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Person-centered care after organ transplantation means not only considering the organ's function and current medication, but also dealing with the person's specific needs, experiences, and resources. The method is based on a collaboration between you and the transplant recipient, with the premise that the person can tell, feel, hear, and be taken seriously.

Taking the transplant recipient seriously

According to research, a number of key aspects are required for one to be taken seriously:

Listen to the person

Our expectations of the outcome of the conversation influence our listening. Professional listening can never be aimless. **Listening shows care, respect, and reciprocity. It also allows the narrator to clarify:**

- a problem, situation or experience
- responsibility and liability
- struggle and suffering
- how to make meaning

When a person is listened to, he can regain some of his once-lost dignity. Being listened to may increase self-esteem and autonomy, and it creates a relationship through telling and listening. **By listening, you show that you take the person seriously.**

Help the person understand what has happened

An educational conversation is a method that aims to give the transplant recipient meaning and understanding. **The person's understanding and learning about their own situation is stimulated during the conversation,** while you learn more about what it means to be human in relation to organ transplantation. The method is based on asking the person two questions:

- **How do you understand your transplant and your situation?**
- **May I tell you how I understand your transplant and situation?**

The answers to these questions serve as the basis for mutual understanding

Help the person understand what will happen

Work in this step begins with the patient material. My life-my health. Go over the various parts, as well as treatment and possible side effects, with the transplant recipient.

Take the person's concerns and symptoms seriously.

- Ask the person to talk about their concerns and fears. Acknowledge any suffering.
- Map and analyse symptom burden.
- Map and analyse obstacles and barriers to a functioning daily life.
- Treat the transplant recipient as a person capable of improving their health.

Make the person feel good and safe in the moment.

Set aside time for both physical and digital visits. Following that, you can begin any digital follow-up for specific areas of focus. **Provide the person with ongoing contact with the same nurse and/or doctor.**

The foundations of rehabilitation

The medical staff requires three special strategies for transplant recipients to be able to rehabilitate and adapt to life with their transplanted organ:

Understand the importance of comparison

The transplant recipient tries to find his new normal by adapting his daily life and changing his behaviour to deal with new routines and challenges. It is impossible to predict what the new normal will look like.

Adaptation is a process as well as a state. The condition indicates that the transplant recipient has successfully adapted to life as a transplant recipient and has settled into the new normal.

Promote acceptance

Before life and daily life can be adjusted, the transplant recipient must accept the transplant and the associated treatment. Acceptance occurs when a person believes that despite lifelong immunosuppressive treatment, they have reasonable conditions and resources to live a functioning life.

Acceptance requires an inventory and analysis of the person's resources: physical, mental, social, spiritual, and financial. These indicate the person's conditions for living a functional life.

Support customization

Living with a chronic condition requires extensive processing and lifelong adaptation to daily life. Adaptation occurs in all aspects of life: physically, psychologically, socially, and in daily life. Frustration, obstacles, and other perceived barriers can all obstruct successful processing.

The transplant recipient must adapt himself and his daily life, but the family must also adapt to the conditions and the workplace must understand the adaptations that may be required.

Care should facilitate adaptation and encourage study or work. Other important roles for successful adaptation include medical social worker, psychologist, physiotherapist, and occupational therapist. Possible actions include:

- Contacting an occupational therapist for activity analysis and energy planning.

One important strategy used by the transplant recipient is to compare the time before the transplant to the time after the transplant. Self-confidence and trust are strengthened to make progress in recovery by mirroring one's recovery and how strength and energy gradually return. **When you assist a transplant recipient focus on progress, their confidence in their abilities grows, giving them the strength to continue self-care.**

The difficulties that exist are listed according to what the person can do on their own and what care can assist with. Examine which coping strategies need to be developed or revised. Tools to promote acceptance are:

- Determine the person's resources and barriers.
- Tools for managing daily life
- Tools for influencing behaviour
- Contacting a physiotherapist for body awareness, acupuncture, relaxing exercises, or massage therapy.
- Contacting a psychologist for CBT and mindfulness training.
- Learning to live with unpredictability and uncertainty.
- Defining when it is appropriate to begin special interventions or extended pharmacological treatment.
- Determining when advanced treatments are required.
- Discussing possible community with other transplant recipients- for many, sharing with others in a similar situation is healing.
- A clear plan for all contacts: how, when, and with whom?

Important keys to an improved health and functioning everyday life for the transplant recipient

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 develops when you are treated as a person rather than as a patient who is only connected to his transplanted organ. Trust is developed through a consistent and ongoing care relationship with the doctor and transplant nurse. They function as an anchor, a central point of contact, and a coach, and should be appointed for every transplant recipient. Demonstrating that the healthcare system works for the person's best interests fosters the ultimate sense of trust.

Security

Security refers to the transplant recipient's belief in himself, ability to manage his existence, and understanding of what is required when one is a transplant recipient. One of the most important aspects of strengthening a person's sense of security is reducing uncertainty and, as a result, strengthening the ability to act in various situations where the transplant and medication affect daily life.

Patience

It takes time and patience to adapt to life with a transplanted organ. Creating a meaningful existence with good routines in everyday life and physical activity can help a person's patience. It is also important to take the transplant recipient's symptoms and side effects seriously, as well as to be sensitive to uncertainty and fears of various kinds. Setting realistic goals in daily life and evaluating them in stages can help strengthen patience. When the road gets tough, the nurse plays a vital role in providing support and encouraging perseverance.

Strength

Living with a transplanted organ requires a lot of strength. Discuss any side effects of the immunosuppressive treatment or other medication, paying special attention to the positive effects. It is important that the person can do their job or study, at least partially.

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