



# ESOT-ETPO Workshop

**WORKSHOP 2: LIVING YOUR LIFE AFTER  
TRANSPLANTATION. PATIENT-CENTRED  
APPROACH AND PEER SUPPORT NETWORK**

19 SEPTEMBER 2023

# Workshop 2: Living your life after transplantation.

## Patient-centred approach and peer support network

The period following transplantation can bring many physical, emotional and social challenges that transplant recipients need to navigate.

To discuss and address these challenges, representatives from patient societies and associations, patient advocates, transplant professionals and allied healthcare professionals gathered at the European Society for Organ Transplantation-European Transplant Patient Organisations (ESOT-ETPO) Workshop 2 on Tuesday, 19 September 2023.

The purpose of the workshop, titled 'Living your life after transplantation. Patient-centred approach and peer support network,' was to learn from the different voices in attendance and explore the power of a patient-centric approach and peer support networks in enhancing life after transplantation.

### My Life-my health

Anna Forsberg, Professor of Transplant Care at Lund University, Sweden, commenced the workshop by presenting 'My Life-my health,' a collaborative project undertaken by the European Society for Organ Transplantation (ESOT) and Takeda<sup>1</sup>. This initiative rose in response to a 2020 survey<sup>2</sup>, which underscored the need for more patient-focused post-transplant rehabilitation.

Discussing the project's vision, Anna remarked, "A life that is gained should also be lived. That's the key theme for this project. We want to focus on the person with an organ, not the organ in the person."

She went on to detail their approach to achieving this goal. The project is dedicated to developing an array of tools for organ recipients, their support networks, the broader society and healthcare professionals. The ultimate objective is to establish a just transplant care system where recipients are not solely reliant on individual healthcare professionals. Instead, the project aims to create a solid support network, nurturing a patient-centred approach.

The project focuses on three fundamental areas. The first centres on enhancing patient literacy, learning and adaptation, recognising that life post-transplantation is a constant adaptation journey due to the chronic nature of the condition. Strategies are therefore required to address the individual learning needs of both patients and their wider support networks over the course of their life.



The second area focuses on raising healthcare professionals' awareness regarding the importance of supporting patients on this adaptation journey, with collaboration and teamwork among professionals being a vital component.

The third critical aspect is nurse empowerment. Anna clarified, "The reason behind this is not to exclude other professionals, but more to emphasise that nurses are often on the frontline. Additionally, nurse-led follow-up is very cost effective, with nurses being specifically trained to deal with everyday situations."

This project was inspired by the work carried out by Anna and Takeda Sweden. It will be adapted and expanded for a global audience within ESOT, incorporating a comprehensive toolkit of resources designed to address the three core focus areas outlined earlier.

For recipients and their support networks, the toolkit includes materials such as a booklet about the adaptation process, a 'workbook' to explore the different aspects of life after transplantation and a booklet for partners and their relatives to support the adaptation process.

For healthcare professionals and the transplant team, the box contains a poster highlighting the different aspects of life that may be affected for the recipients and a brochure explaining the importance of a person-centred care and the foundation of a person-centred rehabilitation process.

The toolkit is intended to act as a starting point for developing a truly patient-centred approach to post-transplantation care.

*"A life that is gained should also be lived. That's the key theme for this project."*

- Anna Forsberg

1. The "My Life My Health" project has been developed under a healthcare collaboration between the European Society for Organ Transplantation (ESOT) and Takeda that aims to benefit patient care.

2. Jansen, N., Maple, H., Forsberg, A., Loud, F., McColaugh, L., Murphy, M., Fuertes, J., Gallego, D., Paredes, D. (2021). Building a bridge between patients and transplant healthcare professionals – a descriptive study. *Transpl Int*, 34: 2098-2105.

## Workshop 2: Living your life after transplantation. Patient-centred approach and peer support network

### What can we learn from each other? Developing a peer support network

The workshop then transitioned into a panel discussion, where the pivotal role of peer support networks for transplant recipients was explored among patient representatives.

Beginning the discussion, Fiona Loud, Policy Director for Kidney Care UK and a kidney transplant recipient, emphasised the value of peer support groups. One of the key resources she highlighted was a Facebook support group, led by Kidney Care UK, that provides an informal space for patients and their families to share experiences, ask questions and find the support they need. She also stressed the importance of patient-reported experiences in patient care, noting how feedback has called for improvements in shared decision-making, which is essential for creating a more patient-centred environment.

Continuing, Pisana Ferrari, a patient advocate and double lung transplant recipient, shared her perspective as someone living with pulmonary arterial hypertension. She explained how patients with rare conditions often remain in their smaller condition support groups and voiced the need for a Pan-European network for peer support.

Aoife Smith, Co-ordinator of Counselling Services for the Irish Kidney association, moved on to discuss the establishment of a national peer support service. She emphasised that the service stemmed from the patients' need to connect with others who had a similar lived experience.

*“This journey will be challenging, but there are ways to live with it and live well with it.”*

- Aoife Smith

Reflecting on the feedback the service had received, Aoife said, “The feedback that we got from the patients that engaged in the service was that they felt more prepared, more confident going into their hospital treatments.” She continued, “It gave them a realistic sense of hope that yes this journey will be challenging, but there are ways to live with it and live well with it.”

Peter Carstedt, Founder and leader of More Organ Donation (MOD) and a two-time kidney recipient, echoed these sentiments when recounting the crucial role peer support networks played over the course of his transplantation journey. He explained that as recipients settle into their everyday lives, other patients offer a unique source of guidance that healthcare professionals may not be able to.

Borislava Ananieva, a founding member of the European Patients' Forum Youth Group and two-time kidney transplant recipient, closed the discussion by sharing the distinctive challenges she faced as a transplant patient in Bulgaria due to the fragmented nature of patient organisations in her country. She underlined the critical role of access to first-hand experiences and patient testimonials in helping others make informed decisions about their healthcare, particularly when considering treatment abroad.



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