



# My Life - My Health

## Train the Trainer Workshop

17<sup>TH</sup> SEPTEMBER 2024

GUY'S HOSPITAL,  
LONDON,  
UNITED KINGDOM

# ESOT My Life – My Health Train the Trainer Workshop Report

## Background

A survey by the European Society of Organ Transplantation (ESOT) and European Transplant Patient Organisations (ETPO) highlighted the need for person-centred rehabilitation among transplant recipients.<sup>1</sup> The My Life – My Health (MLMH) project is a response to this need, promoting a focus on the person with the organ, rather than just on the organ.

On 17 September 2024, a workshop at Guy’s Hospital, introduced healthcare providers (HCPs) to MLMH, a collaborative initiative between ESOT and Takeda to support coherence and adaptation after solid organ transplantation. The workshop was moderated by Hannah Maple (Consultant Transplant and Dialysis Access Surgeon from Guy’s Hospital, London) and presented by Anna Forsberg (Professor of Transplant Care from Lund University, Sweden).

## Introduction to My Life – My Health Project

After welcoming participants, Forsberg shared the mission of MLMH: “To empower organ recipients to navigate their post-transplant journey, recognising recipients as individuals with unique needs beyond their medical condition.” She described how the person-centred care required to achieve this goes beyond patient-centred care, stating, “Person-centred care recognises that patients are more than their illness; they are individuals who live the majority of their lives outside of clinical settings.” Through this person-centred lens, Forsberg outlined the three main objectives of MLMH:



1. **Patient literacy, learning, and adaptation** – To support patients in their unique learning journey. However, Forsberg emphasised that HCPs must also learn and evolve in their understanding of the patient experience.



2. **Raising awareness among HCPs** – To enhance HCP capabilities to support individual patient’s adaptation and health balance.



3. **Nurse empowerment** – To empower transplant nurses as critical stakeholders in day-to-day self-management support to achieve the first two objectives.

The ambition is to drive a paradigm shift where “A life gained, should also be lived.”

Forsberg described the art and science of transplant care as promoting health by supporting patient adaptation. “Central to this adaptation is acceptance,” said Forsberg. “Without acceptance, patients may resist the transition from illness to health.” However, significant uncertainty, especially fear of organ rejection, can hinder this acceptance.<sup>2</sup>

In addition to adapting to their new normal, patients must also navigate complex self-management, including infection control, medication adherence, symptom management, and lifestyle changes.<sup>3</sup> The emotional and psychological challenges they face occur throughout their journey—from diagnosis to long-term recovery. “Navigating these challenges requires a collaborative, multidisciplinary team approach, with the patient ideally at the centre of that team,” said Forsberg.



## The My Life - My Health Toolkit Box

Forsberg introduced the MLMH toolkit box as a resource to facilitate a person-centred, team-based approach. Developed using a grounded theory approach, the toolkit draws on years of research and practical experience. Originally created for individuals with Parkinson’s disease, it quickly proved valuable for other chronic conditions, including organ transplantation. “A key insight emerged: people, universally strive for social belonging, whether within families, workplaces, or patient communities,” Forsberg noted.<sup>4</sup> For transplant recipients, re-establishing this sense of belonging involves navigating four stages of understanding and adaptation, which are addressed in the toolkit: comprehension, acceptance, adaptation, and balance.

The three main components of the MLMH toolkit are:



1. **HCP brochure:** This guide provides a structured overview of person-centred care and how it can be implemented. Forsberg emphasised that person-centred care is a mindset shift that doesn’t require additional financial resources.



2. **Patient’s box:** Presented as a ‘gift’ for patients, this tangible tool includes a brochure that explains the adaptation model to help patients understand and manage their transition post-transplant. There is also a brochure for spouses or relatives to address their unique challenges in supporting the transplant recipient.



3. **Life Balance Puzzle workbook:** This tool helps patients reflect on different aspects of their life post-transplant, enabling them to record concerns and track progress. It is designed to support patient-led discussions during clinic visits, empowering patients to prioritise their concerns and collaborate more effectively with their HCPs.

## Open Discussion

Furnished with their own physical copies of the MLMH toolkit, workshop participants engaged in a dynamic discussion, sharing their thoughts and questions about the materials.

- **Resource constraints:** One participant highlighted the lack of a psychologist in their Trust, praising the toolkit for its value in resource-limited environments. Another noted seeing a potential benefit for most of their patients, reinforcing its impact.
- **MLMH delivery:** A key question arose about who could provide person-centred care. Forsberg clarified that while all HCPs can use the toolkit, delivery depends on time and interest. She encouraged HCPs from all disciplines to participate, citing Sweden’s nurse-led follow-ups as an example.

<sup>3</sup> Developed by Forsberg based on Schaefer-Keller & De Geest, 2007.

<sup>4</sup> Rosengren L, Forsberg A, Brogårdh C, Lexell A. Social Belonging as the Main Concern for Achieving Life Satisfaction When Adapting to Parkinson’s Disease. *Int. J. Environ. Res. Public Health* 2021, 18, 8653. <https://doi.org/10.3390/ijerph18168653>

- *Ensuring consistency:* A concern was raised about maintaining consistency in care, as patients often encounter multiple teams and different teams pre- and post-transplant. Forsberg stressed the importance of a team-based approach, recommending that healthcare teams watch the MLMH course together to ensure a unified ideology.
- *Cultural Sensitivity:* Participants were interested in the toolkit's adaptability for diverse and ethnic minorities. Forsberg noted its cultural flexibility, citing her experience in Saudi Arabia and affirming its broad applicability.
- *Paediatrics:* The application of MLMH in paediatric care sparked great interest. While not yet tailored to adolescents, Forsberg shared ongoing efforts to create materials for younger patients, including online materials. A paediatric HCP highlighted the role of play specialists in emotional support, sparking further conversation about how adult care could learn about person-centredness from paediatric care practices.
- *Engaging reluctant consultants:* The session concluded with a question about engaging consultants resistant to person-centred care. Forsberg shared her belief that everyone who enters healthcare does so with a capacity for empathy and that even those who seem resistant to person-centred care could be encouraged when they see the positive impact it has on patients.

## Applying MLMH Tools in Practice

The workshop transitioned towards practical applications of the MLMH tools, encouraging participants to explore how these could be integrated into their practices.

One participant suggested using the Life Balance Puzzle workbook to help patients prepare for outpatient appointments by outlining their concerns in advance. Forsberg endorsed this idea, noting that it could foster a shift from the traditional model, where HCPs often prioritise their own concerns over those of the patient.

Another participant emphasised the importance of having all staff in their practice complete the MLMH course. Since the course is free, they believe the resource is both accessible and would help to standardise care across the team. Forsberg agreed, stressing that the no-cost aspect of the toolkit and course is critical for spreading knowledge and improving practice.

Forsberg provided a practical example of person-centred care from her lung transplant outpatient clinic, where three nurses, each assigned to their own set of patients, worked collaboratively to form a cohesive care team. This approach allowed for continuity without requiring every nurse to be familiar with every patient's details. She pointed out that while patients don't expect to see the same HCP every day, seeing familiar faces even two or three times can significantly enhance their care experience. It agreed that having a named nurse or physician who follows the patient from their initial visit through follow-up appointments could be an effective model for continuity of care.

The discussion also touched on the issue of gratitude, with Forsberg highlighting the sometimes-unrealistic expectation placed on transplant patients to constantly feel grateful for their procedure. This pressure can lead to emotional distress, particularly for those experiencing complications or grappling with survivor's guilt. The group concurred that it is essential to avoid imposing societal or professional expectations on transplant patients without considering their emotional well-being.



## Workshop Reflections

The final open discussion of the workshop enabled participants to share their reflections:

- *The power of language:* Participants discussed how certain phrases used in patient interactions, such as “this is a good kidney for you” or “you’re lucky,” can unintentionally pressure patients to feel grateful. There was a consensus on the importance of being mindful of language to avoid adding emotional burdens.
- *Pre-transplant preparation:* One participant suggested integrating the Life Balance Puzzle into pre-transplant education, helping patients establish realistic expectations and reduce the risk of post-transplant disappointment.
- *The value of setting expectations early:* Another participant stressed the importance of tracking quality-of-life outcomes and setting realistic expectations early in the transplant process to improve patient satisfaction and outcomes.
- *Making care more meaningful:* Reflecting on the patient experience, participants agreed that even less frequent consultations could become more meaningful by using the Life Balance Puzzle, encouraging patients to express their concerns more effectively.

Forsberg concluded by emphasising that small, incremental changes can have a significant impact in promoting person-centred care and improving the overall quality of care and patient outcomes.

## Procuring Toolkit Boxes and the Life Balance Puzzle

Participants were advised on how to order additional MLMH toolkits and materials, either through the ESOT website or by contacting ESOT directly at [askme@esot.org](mailto:askme@esot.org).

## Education Course

The Education Course on Transplant Live provides resources to support coherence and adaptation after transplantation.<sup>5</sup> It includes a lecture on person-centred communication and care by Forsberg. The course can be accessed through the ESOT website, where HCPs can watch videos, explore the toolkit, and further empower nurses and other stakeholders involved in post-transplant care.

## Key Takeaway

The workshop concluded with the take-home message: when HCPs view the patient as a person rather than just focusing on their medical condition, care becomes more effective and precise. This person-centred approach is essential for improving outcomes and delivering tailored, empathetic care.



<sup>5</sup> European Society for Organ Transplantation. Supporting coherence and adaptation after transplantation. ESOT Transplant Live. <https://www.esotransplantlive.org/course/view.php?id=134&section=1>