



# ESOT Patient Inclusion Workshop:

**Challenges to a practical  
approach to '*Staying healthy*'  
for a transplant**

# Part 1

14:00	Setting the scene – Being realistic about keeping a healthy lifestyle	10 min	Hannah Maple (UK)
14:10	Identifying the challenges in meeting 'healthy' lifestyle goals as a transplant patient. Which part of life is the hardest? Which ones are easier?	10 min	Fiona Loud (UK)
14:20	How to communicate sensitive topics such alcohol consumption, smoking, and body weight with your doctor, physicians and health care provider?	15 min	Inês Mega (Psychologist)
14:35	Intro to the ESOT Patient HUB (Therakos Project)	10 min	Nichon Jansen (The Netherlands)
14:45	Intro to TransplantGO! (Chiesi Project)	10 min	Veronica Carbone (Grupo Mayo)
14:55	My Life – my health update (Takeda Project)	10 min	Anna Forsberg (Sweden)
15:05	Q&A	10 min	
15:15	Wrap up and Intro to Part 2 of the Workshop	05 min	

# Part 2

15:30	Break out group discussion <ul style="list-style-type: none"><li>• Fatigue and Fear</li><li>• Spectrum of Physical Activities</li><li>• Mental Health Activities</li><li>• Overcoming financial/geographical/physical/comorbidity barriers</li><li>• Body image – scars and weight</li><li>• Alcohol and Smoking</li><li>• Diet and eating healthy</li><li>• Adherence – medicine and technology</li></ul>	30 min	
16:00	Sharing the outcomes of the breakout discussion	15 min	One representative from each group
16:15	Wrap up & Concluding Remarks	15 min	



# Setting the scene: Being realistic about keeping a healthy lifestyle

**Hannah Maple**

Consultant and Dialysis Access Surgeon

Guy's and St Thomas' NHS Foundation Trust

# Disclosure of conflicts of interest

Nothing to declare



*You are welcome to share details of this presentation responsibly and with due credit on social media.*

# Why do I need to think about living a healthy lifestyle?

## Insights into the mind of a surgeon

- Why do I need to see a surgeon?
- What is my surgeon thinking about and why?
- What happens if I ignore them?!
- What does my surgeon expect from me?

# The best analogy

**26.2 miles**

**Highs and lows**

**Some of London's iconic landmarks**

**Everyone must run the same distance**

- Some find it easier than others

**The support is amazing**

**London at it's best**







# The start / Miles 1-5: Workup



# The start / Miles 1-5: Workup

## 3 different start lines

- For example: Pre-dialysis, Haemodialysis, Peritoneal dialysis

## Some have run a marathon before

- First transplant
- Second transplant

## Some are more scared than others

- Don't worry!
- The crowd has your back!



## Tests

- Blood tests
- Heart tests
- Imaging

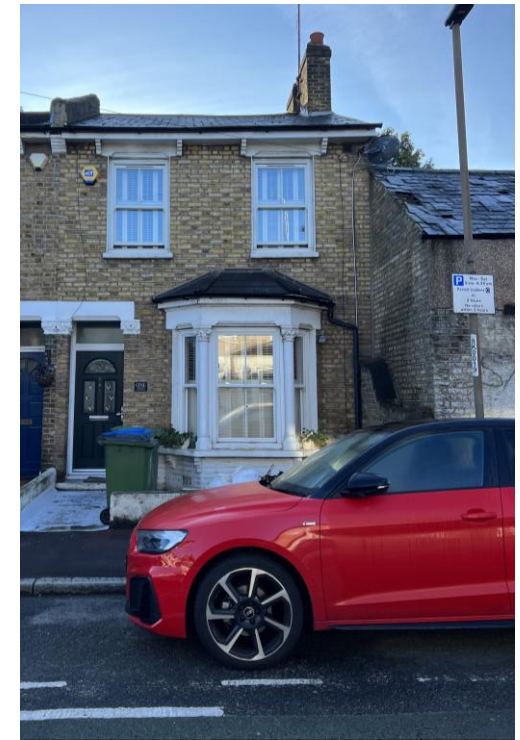
**MY HOUSE!**  
**(The Surgical Appointment)**

# Mile 5: The surgical appointment

## 3 main questions

1. If I want to transplant you, where will I put the organ and how?
2. Are you fit enough for a big operation +/- other operations?
3. Is there anything else I need to be thinking / worrying about?  
Aka: Am I fixing one problem and creating another one?

- Other medical issues
- Infection risk
- Cancer risk
- Tablet taking
- Psychosocial factors



# Miles 6-12: The Waiting List

## Crucial

- Stay as well as possible
  - If you don't, you'll pay for it later
- Goldilocks approach
  - Not too fast
  - Not too slow
- Slow and steady wins the race
- Still a long way to go



## Clinically

- Some sail through
- Some stop +/- restart
- Some really struggle
- Some stop

# Mile 12: The Transplant (p.s. not half way...)



The iconic moment

True to scale!



# However... It's just the beginning!

Finish line – this way!



You must run in the opposite direction...



# Miles 13-21 = Post-transplant phase

## Things start to hurt!

### Even for those sailing through...

- Full of uncertainty
- Long +/- boring!
- Consistency is key

### For some...

- Really painful
- Question life choices – “why did I agree to this?”
- People start to stop and need help

## Where you see the difference



## Clinically

- Some sail through
- Some stop +/- restart
- Some really struggle
- Some stop...

# Miles 21-26.2 – final push (> 3 months)

**The home straight (hopefully!)**

## **Can feel euphoric**

- Worst is behind you
- The end is in sight
- Lots of people cheering you on

## **Can feel awful!**

- Full of uncertainty
- Stop-start
- Go on forever!
- "When is this going to end?"



## **Clinically**

- May get lucky – no problems
- Infections
- Cancers
- Other medical problems
- Surgical issues

# The finish line



# What does my surgeon expect?

**You don't actually have to be able to run a marathon!**

## **Respect for the process**

Different to getting a new hip / knee

## **We want to transplant you**

Safely

Best interests

If we think you will make it

## **A note on weight / BMI...**

- **It is important**
- **No magic number**
- **Other things matter**
  - Rest of you (other issues / complexities)
  - Abdominal girth / weight distribution
- **Not just about the transplant**
  - Managing complications
    - More likely – significant
    - More challenging – fewer options

# In summary

**Having a transplant is like running a marathon**

**26.2 miles**



**A transplant is a big operation**

**Highs and lows**



**Good parts and bad**

- Respect the process

**Some of London's iconic landmarks**



**Key milestones – getting home, no more dialysis**

**Everyone must run the same distance**



**The key to an easy race / recovery is training**

- Some find it easier than others

- What you put in, you get out

**The support is amazing**



**We are here!**

**London at it's best**



**Modern medicine at it's best**



**Thank you**



# Identifying the challenges in meeting 'healthy' lifestyle goals as a transplant recipient

Fiona Loud, Kidney Care UK [www.kidneycareuk.org](http://www.kidneycareuk.org)

Member of the ETPO Steering Group

ETPO = European Transplant Patient Organisations

# Disclosure of conflicts of interest

Nothing to declare



*You are welcome to share details of this presentation responsibly and with due credit on social media.*

# Where do these insights come from?



**Kidney Care UK report, 'Transplant care in the UK'**  
**Kidney Care UK social media**  
**Common patient themes**

# Where exactly is the finish line?



# Meeting emotional and psychological needs

Kidney Care UK survey of 670 patients found unacceptable variation in the care people receive, including mental health support. There were examples of excellent care and support, but many people reported unmet psychosocial needs. 1/5 had been called for a transplant which did not go ahead

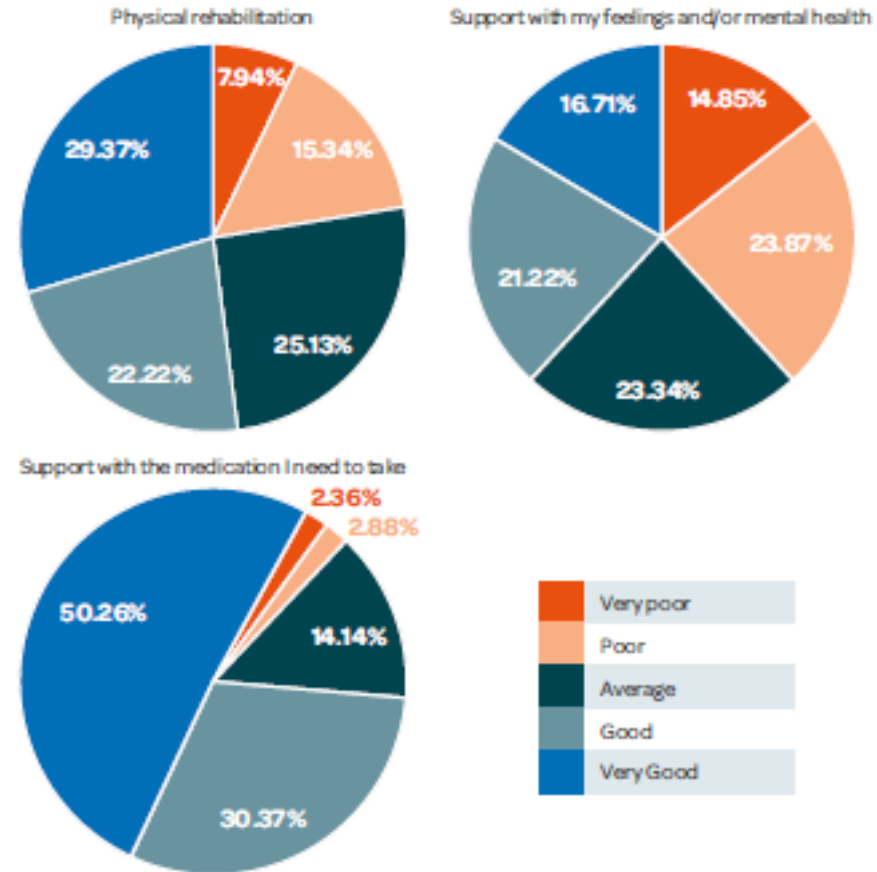
“Zero mental health support – it feels like you’re expected to be grateful and happy post-transplant but it’s a huge, life changing event”

“The transplant work up is agonising....the whole thing has been emotionally exhausting”

<https://kidneycareuk.org/about-us/policy-updates/transplant-care-in-the-uk-a-patient-perspective/>

# What do recipients think?

Figure 4: Please rate your level of satisfaction with the support you received after your transplant, in the following areas:



Rehabilitation

Medication

Mental health support

# Diet



**How to eat well to stay well** is one of our most common questions at Kidney Care UK.

Moving from a low potassium diet to a more normal yet healthy diet post transplant is important and should be enjoyable

Check out [www.kidneykitchen.org](http://www.kidneykitchen.org) for videos, recipes and full recipe collections (from dietitians)

Eat Well Spend Less, South Asian Recipes, Safe Weight Loss, Classic recipes and African and Caribbean recipes

Much debate on plant-based and keto diets – speak to a dietician before making radical changes

Some views that post transplant dietary guidelines are a missing link

Special issue of Transplant International <https://www.frontierspartnerships.org/research-topics/45/living-well-after-organ-transplantation>

# Weight loss

Weight loss – what we eat and what we do

Many need to lose weight to get on the transplant list or put it in post-transplant

New medications (Ozempic, Mounjaro etc) can help, where prescribed and \*needing caution\*

Many can only get this if they pay and not through the NHS

[Home](#) > [Weight Loss Treatment](#) > Mounjaro



Image shown is for illustrative purposes only

## Mounjaro (Tirzepatide)

All Mounjaro doses are available to new and returning patients.

[Get started](#)

**In stock.** Prices from £128.98

Simply fill in a brief questionnaire. One of our doctors will review your order and prescribe a suitable treatment. [How to Order](#)

# Exercise

- **Regaining fitness and confidence**
- **Being active post transplant (not running the marathon!)**
- **Pilates/Yoga**
- **Walking is free**
- **Kidney Beam, subscription service <https://www.kidneybeam.com/>**
- **Being active with your transplant <https://transplant.org.au/living-with-your-transplant/post-transplant-fitness/being-active-with-your-transplant/>**

## How hard should I exercise?

Any physical activity that you can do is better than nothing. Even gentle walking will decrease your sitting time and improve your health. However, for greater benefits, your physical activity needs to be of moderate or vigorous intensity.

The **‘Talk Test’** is a simple way to judge the intensity of the activity you are doing.

- Moderate intensity — you should be able to talk but not sing.
- Vigorous intensity — you will not be able to say more than a few words without getting out of breath.

# Avoiding infections

- Sickness can be experienced differently when immunocompromised

Is it a big problem? Is it going to get worse?

- Hard to hear but “you are more likely to develop infections while receiving immunosuppressant therapy and any infections may be worse than normal. You should report any signs of infection to your doctor”.
- It’s a whole new language and not everyone speaks it
- Primary care might be very wary – transplants are not common
- Get your vaccinations
- Take care with potential sources of infection: ice from ice machines, foods which might be risky if immunosuppressed e.g. blue-veined cheese, undercooked eggs, live yoghurts

# Looking after your skin and your transplant in the heat

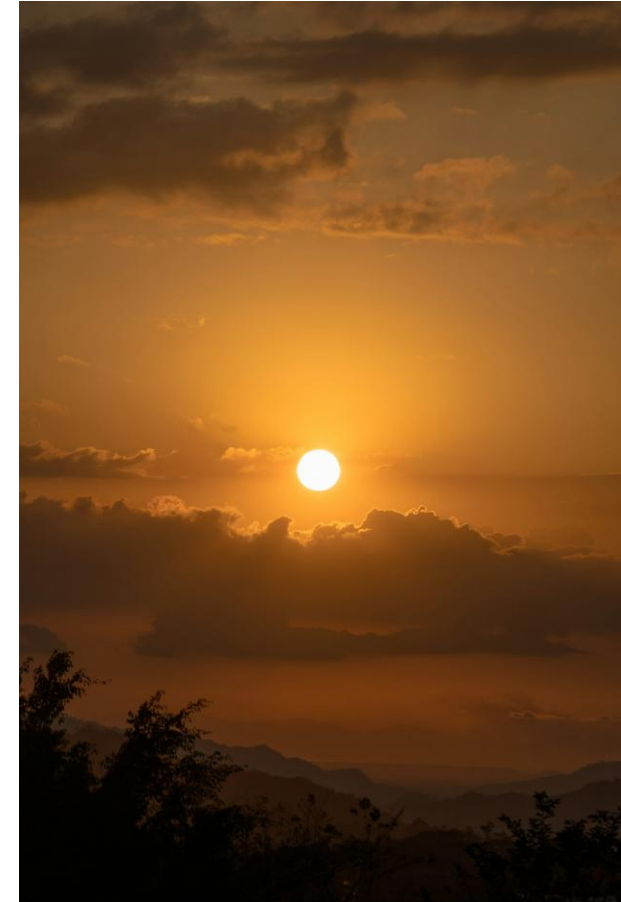
Keeping the fluid balance

Moving from don't drink – Drink – Drink lots!!

Sun protection – immunosuppressants

Seeing a dermatologist

<https://kidneycareuk.org/kidney-disease-information/living-with-kidney-disease/stay-safe-in-heat-and-sun/#:~:text=Skin%20cancer%20risk%20in%20advanced,groups%2C%E2%80%9D%20says%20Dr%20Hextall>





# Thank you

Be kind to yourself



# How to communicate sensitive topics with your doctor, physicians and health care provider?

**Inês Mega**

Clinical Psychologist and Psychotherapist

Transplantation Unit – Hospital Curry Cabral, ULS São José

Lisbon, Portugal

# Disclosure of conflicts of interest

Nothing to declare

# The challenge



*“I am myself and my circumstances”*

Ortega y Gasset

# The challenge

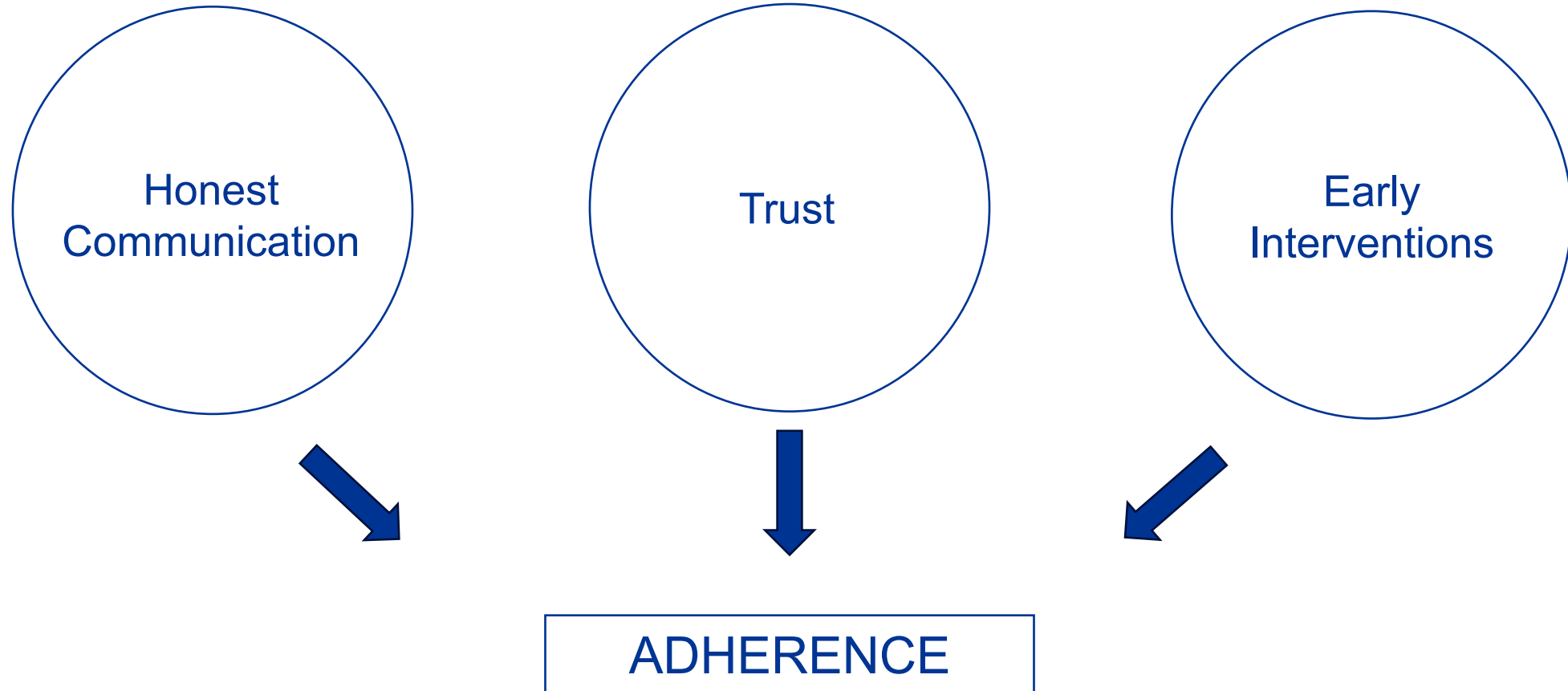
## Transference

refers to patients unconsciously projecting feelings, attitudes and desires, from past relationships onto their healthcare professionals.

## Counter-transference

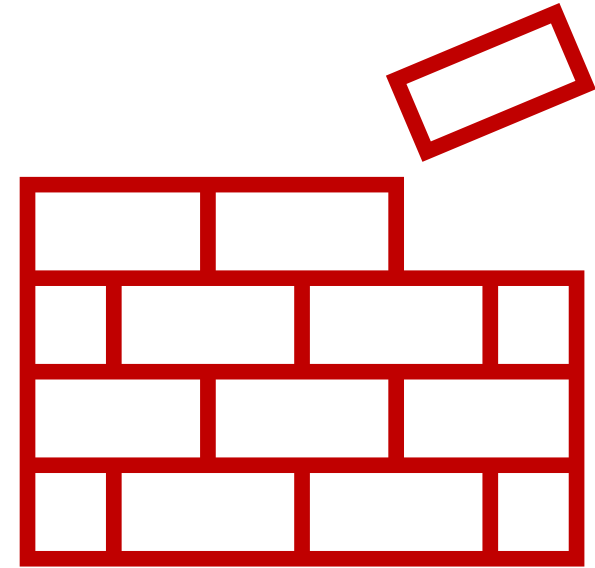
it's the healthcare professional's unconscious emotional reaction to the patient.

# Why this matters?



# Common Patient Barriers

- Fear of judgment/being denied transplant
- Shame and stigma
- Not understanding medical relevance
- Cultural/personal sensitivities



# What One Can Do - before the appointment

- Prepare honest answers
- Write down questions
- Bring a support person if helpful
- Understand it's medical, not personal

# What One Can Do - during the conversation

- Scripts for initiating difficult topics
- "I want to be completely honest about..."
- "I'm worried about how this might affect my care..."
- Ask for clarification on medical reasoning

# How Healthcare Providers Can Help

- Create safe, non-judgmental environment
- Explain medical reasoning upfront
- Use motivational interviewing techniques
- Acknowledge patient concerns
- Share resources
- Be aware of possible bias and prejudices.

# Building Trust Together

- Vulnerability + Openness + Transparency = Trust → Psychological Safety
  - Trust depends when the involved parties show openness
- Shared/Participatory decision-making
- Regular check-ins and follow-up

*“People don’t care how much you know, until they know how much you care.”*

Theodore Roosevelt



# Thank you

[inesmega18@gmail.com](mailto:inesmega18@gmail.com)



# Introducing...

# ESOT Patient HUB

**Nichon Jansen,**

Member of the ETPO Steering Group

*This project is possible thanks to the unrestricted grant support from*



# Currently, the ESOT page is not the most navigable for a patient looking for helpful information

The screenshot displays the ESOT website interface. At the top left is the ESOT logo, "The European Society for Organ Transplantation". To its right is a horizontal navigation bar with colored buttons for various societies: ECTORS, ECTTA, EDTCO, EKITA, ELITA, ELPAT, EPITA, VCA, Education, Basic Science, ETAHP, and YPT. Below this is a main navigation menu with dropdown arrows for "About", "Events & Education", "Research & Projects", "News & Media", and "Community". A search bar is located on the right side of the main navigation, with "LOGIN" and "Not a member?" links nearby. The "Research & Projects" dropdown menu is open, listing items such as "The ESOT registries platform", "Transplant International", "ESOT Guidelines", "Task forces", "Projects", "Public Affairs", and "EU-funded Projects". Below the navigation, the main content area features a large blue banner with the text "What can we help you with?" and "Filter results for:" followed by buttons for "Healthcare Professionals" and "Interventions". To the right of the banner is a search bar with the text "Search" and a magnifying glass icon. Below the search bar is a link that says "Don't need the search bar? Close it here". The main content area also features a section titled "ESOT Strategic 2030" with a sub-heading "ESOT Strategic 2030" and a paragraph of text. To the right of this section is a vertical list of topics: "Biomarkers", "COVID-19 Vaccine Studies", "Extracorporeal photopheresis (ECP)", "ENGAGE Consensus", "Enhancing post-transplant care", "HLA desensitisation platform", and "Quality of Life after Liver Transplantation". At the bottom right of the main content area is a graphic titled "Plan" with several colorful icons representing different aspects of transplantation.

# Even on the ESOT Patient Inclusion Initiative page, it is not easy to know which webinar, which project will help you in your current stage of the transplantation journey

The screenshot shows the ESOT website navigation bar with the logo and various society abbreviations (ECTORS, ECTA, EDTCO, EKITA, ELITA, ELPAT, EPITA, VCA, Education, Basic Science, ETAHP, YPT). Below the navigation bar, the 'Ongoing events & initiatives' section lists three items: ESOT Congress, Patient Masterclasses, and Patient HUB. The 'Past events & initiatives' section lists ten items, including ESOT Congress 2023 workshops, a 2021 value-based care event, a 2021 patient inclusion group meeting, a 2019 advisory board meeting, a joint EPITA/EDTCO/ETAHP symposium, a TLJ 2.0 event, a Twitter chat, and an alliance mission statement.

The screenshot shows the ESOT website navigation bar. Below it, the 'Webinars & Video Library' section lists seven items, including a webinar on transplant patient journey, two COVID-19 pandemic coping sessions, two TLJ 2.0 Learning Workstream sessions, and an ESOT Congress 2021 online symposium. The 'Reports' section lists three items: an ESOT TLJ Consensus Conference Highlights Report, a COVID-19 pandemic webinar report, and a TLJ 2.0 Learning Workstream report from a patient perspective.

# Solution?

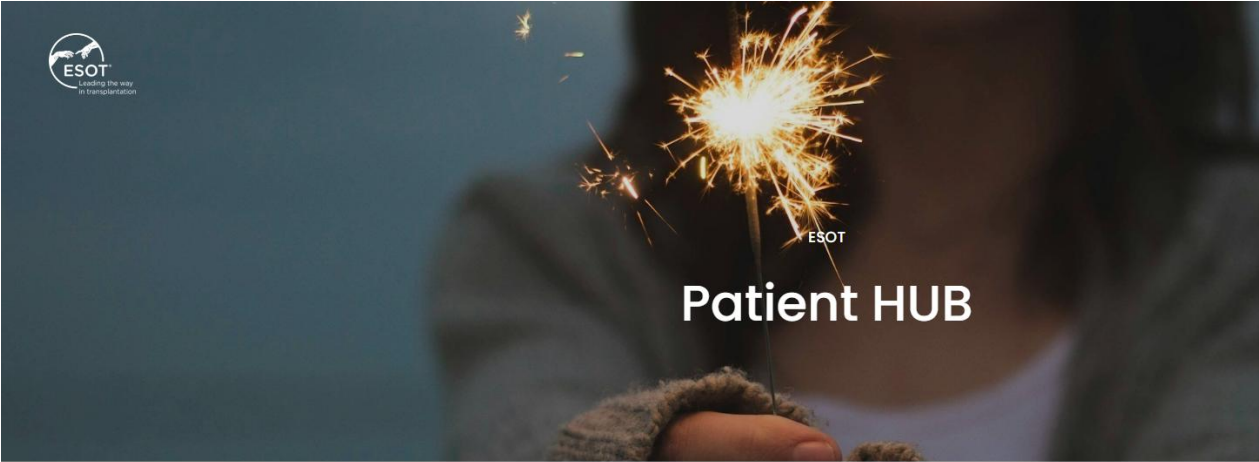
# The ESOT Patient HUB!!

**A new designated digital platform designed to place patients and caregivers at the heart of the transplant journey**

# Aims & Objectives

- To serve as a space for knowledge sharing between clinicians, patients, and caregivers, strengthening a more holistic approach to care
- Offer reliable, accessible, and up-to-date information that empowers patients to understand better and manage their health
- A centralised platform for all Patient related activities hosted under ESOT
- Equitable access to knowledge and education across the transplant community at every stage of transplant care
- Serve as a repository for multilingual, multi-faceted sources across Europe
- Easily navigable, and filled with interactive tools to help the patients

# First Look...



### Subtitle

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For Healthcare Professionals

[Learn more](#)



For Patients

[Learn more](#)

# First Look...



## For Patients

### ESOT's Patient Inclusive Initiative

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[View more](#)

### Workshops and Webinars

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[View more](#)

### See what's happening in your country

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[View more](#)

### Through the Transplant Journey

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[View more](#)



## Through the Transplantation Journey

<h3>The Pre-transplant Phase</h3> <p><a href="#">Learn more</a></p>	<h3>The Waiting List</h3> <p><a href="#">Learn more</a></p>	<h3>The Surgery</h3> <p><a href="#">Learn more</a></p>
<h3>The Post-transplant Phase</h3> <p><a href="#">Learn more</a></p>	<h3>Patient Support and Community</h3> <p><a href="#">Learn more</a></p>	<h3>Additional Resources</h3> <p><a href="#">Learn more</a></p>

# First Look...

## Workshops and Webinars

ECP HCP Kidneys Liver  
non-organ specific patients  
Q Search

**Webinar**  
**Quality of life after liver transplantation: an ESOT seminar for patients**  
Monday 3 June 2024  
17:00 - 18:30 CEST

Quality of life after liver transplantation: an ESOT seminar for patients

**Workshop**  
**The Patients' Journey Around Immunomodulation and Rejection**  
Tuesday 23 April 2024  
16:30 - 18:30 CEST

ECP Workshop - The Patients' Journey Around Immunomodulation and Rejection

It all begins with an idea.

# How can you help?

## See what's happening in your country

- Send us your suggestions for resources to add to this page
- No language/cultural barriers
- Help create a robust repository of helpful information for every aspect of the transplant journey

## Through the Transplant Journey

- Sharing your testimonies and stories on coping with your transplant journey

### See what's happening in your country

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[View more](#)

### Through the Transplant Journey

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[View more](#)

**Volunteers to test the platform are welcome! Please reach out to [supriya.barve@esot.org](mailto:supriya.barve@esot.org)**

# What is the future for the ESOT Patient HUB?

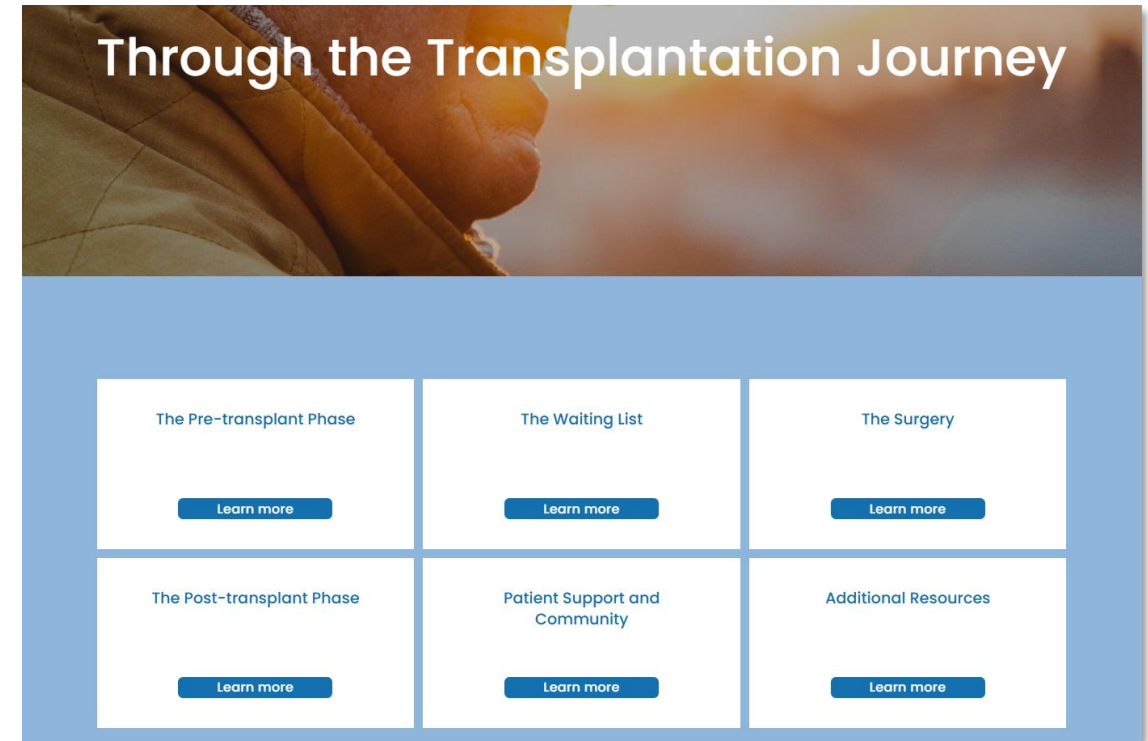
# Before and after the launch

## Before –

- **Gathering valuable patient feedback**
- **Compiling the resources shared**
- **Creating bespoke content for each section of the HUB**
  - Informative texts from clinicians, nurses, patient advocates, patients, and caregivers

## After -

- **Interactive online workshops**
- **Live Q&As**
- **Forums**
- **Maintaining up-to-date information**





**Thank you**

# A SPECIAL UNIQUE PROJECT

**Empowering patients through knowledge and informed decision-making**

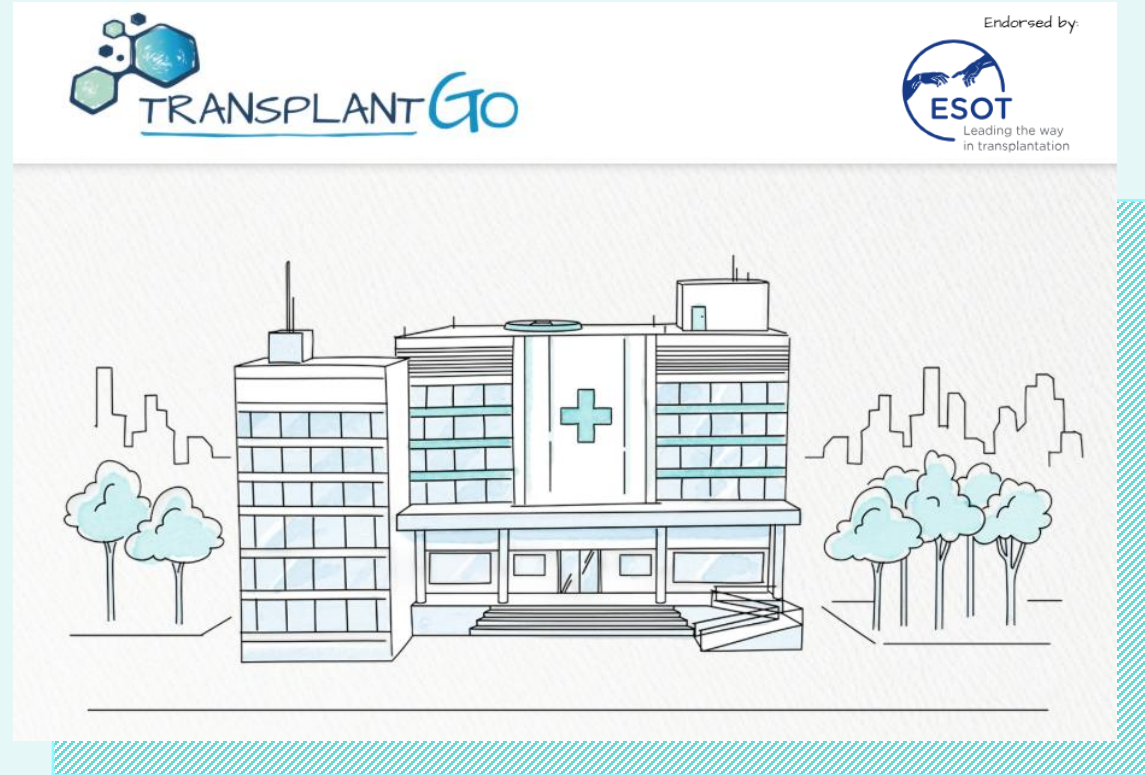
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# 01 INTRODUCTION

We are expanding the Patient Diary's impact through a **Patient Educational Platform** called **TransplantGO** designed to support kidney, heart, lung, and liver transplant recipients.

TransplantGO aims to **enhance well-being, empower patients, improve health literacy**, and ultimately **contribute to better post-transplant outcomes**.

Currently available in English, the platform is in its **demo phase, featuring content for kidney transplant recipients**.



PATIENT EDUCATIONAL PLATFORM

# 02 THE STAKEHOLDERS



Endorsed by:



The European Society  
for Organ Transplantation

Sponsored by:



Scientific and Medical Communication:



# 03 PLATFORM EXPLORE

Please, **scan the QR code** to download a short document with:

- A brief **overview** of the project.
- The **link to access** the demo platform (registration required).
- A link to a **short feedback survey**.

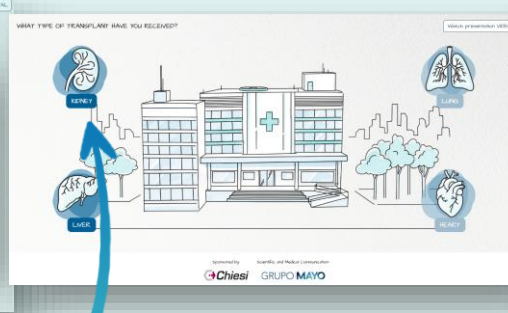
**When convenient, please take some time to explore the document.**



# 04 PLATFORM ACCESS



Access <https://transplantgo.com> and explore the platform!

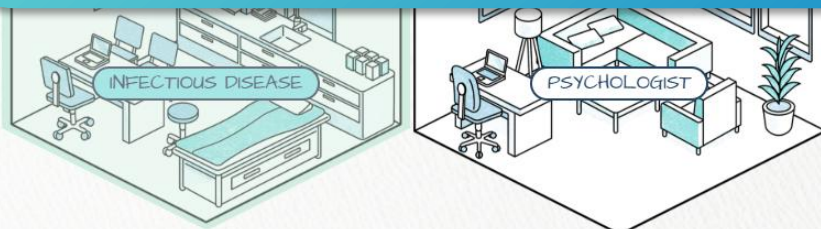


Only the kidney section is available.

### Your Kidney Transplant: Frequently Asked Questions (FAQs)

1 Why has my creatinine level increased, and what could it mean for my transplanted kidney?

- Does this seem like something you would explore on your own?
- Do you think this kind of platform would be useful?



every day for the rest of your life. These medicines help protect your new organ by keeping your immune system from attacking it.

#### → Important:

- Never stop taking these medications, even if you feel completely well.
- Never skip or change doses without talking to your transplant team first.
- If you miss a dose, contact your team right away for advice.

your health. You're at a higher risk for infections, so take precautions—wear a mask when necessary and avoid close contact with anyone who's sick. With the right safety measures, you can maintain meaningful relationships while protecting your health.

# 06 YOUR FEEDBACK



After you've had a chance to explore the TransplantGO platform, **please use the link in the pre-read document to complete the feedback survey:**

**<https://es.research.net/r/MXZV7DH>**

Your feedback is essential to help us shape a *meaningful and useful tool* for the transplant community!

Thank you so much for your collaboration in helping us develop this valuable educational resource, which will have a lasting impact on other transplant recipients!



# THANK YOU!

For inquiries regarding the platform's functionality, please contact

[contact@transplantgo.com](mailto:contact@transplantgo.com)

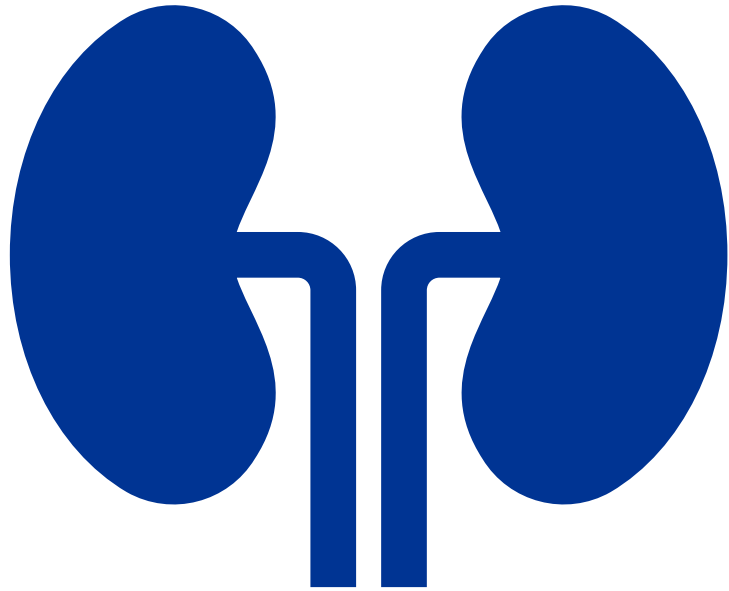


# My life-my health

ESOT-ETPO Workshop

An update by

Anna Forsberg-professor at Lund University in  
Sweden



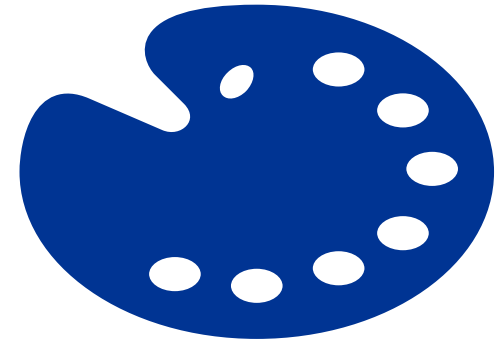
# REHABILITATION AFTER SOLID ORGAN TRANSPLANTATION

*A life gained, should also be  
lived.*

# Transplant Care

The art and science of transplant care is **health promotion** by supporting **acceptance** and **adaptation** as a process towards health.

The transition from illness to health is facilitated when uncertainty is relieved and self-efficacy is strengthened.



# Key points from a short-term patient perspective

## Essentials in the early rehabilitation process

- Start already before transplantation with **PREHABILITATION**
- Provide a structured **ROAD MAP** for the organ recipient including the initial rehabilitation the first 3-6 months.
- Acknowledge that rehabilitation is not merely physical but a **MENTAL** process that needs a structured plan.
- Perform a **RISK-BENEFIT** analysis with the organ recipient in relation to various restrictions and recommendations to facilitate a sound adaptation.
- Involve the primary family caregiver e.g. the spouse.



# Key points from a long-term patient perspective

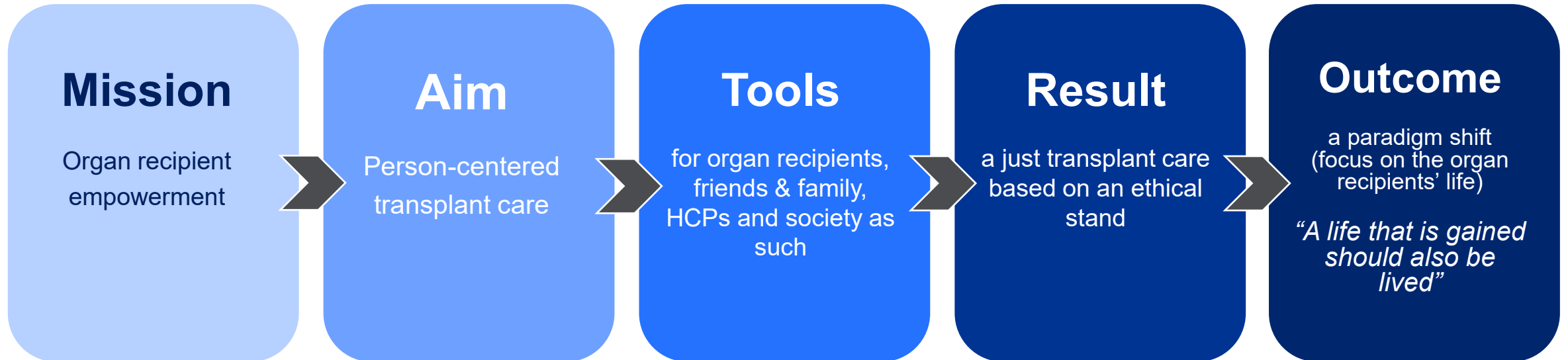
## Essentials in the long-term rehabilitation process

- Provide a structured ROAD MAP for the organ recipient.
- Ongoing education and adaptation support is important.
- Acknowledge that rehabilitation is not merely physical but a MENTAL process that needs a structured plan.
- Understand that being an organ recipient is being in uncertainty.
- Support being part of a patient organization to establish a social belonging and peer support.



# Vision and Mission

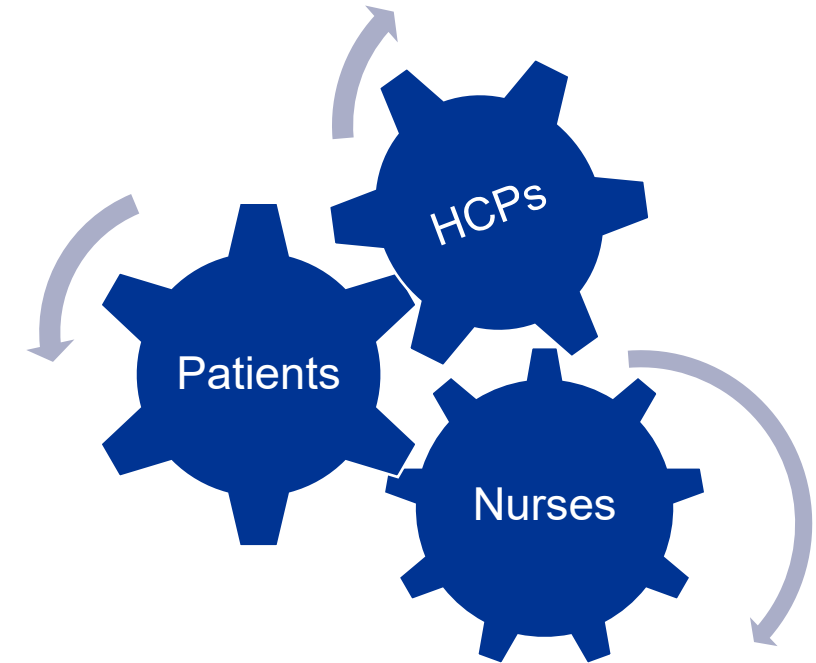
**Vision: Focus on the person with an organ, NOT the organ in the person**



# Objectives

The project My Life – My Health (MLMH) was developed to achieve 3 objectives:

- 1. Patient Literacy, Learning and Adaptation:** Support the patient learning journey, with a focus on individual learning needs. **The toolbox in different languages.**
- 2. Healthcare Professionals Awareness:** Raise HCP awareness and HCP capability to support the individual patient's adaptation and Health Balance, working as a team: **An online course about: How to support coherence and adaptation after solid organ transplantation.**
- 3. Nurse Empowerment:** Empower transplant nurses as critical stakeholders in day-to-day self-management support to achieve objectives 1 and 2. **Workshops in London, Barcelona and Bologna.**



# Education course - available on Transplant Live

## Supporting coherence and adaptation after transplantation

The European Society for Organ Transplantation (ESOT) website header includes navigation menus for 'About', 'Events & Education', 'Research & Projects', 'News & Media', and 'Community'. A search bar and 'MEMBER LOGIN' link are also present. The main content area features a blue banner with the title 'Enhancing post-transplant care'. Below the banner, text describes a collaboration between ESOT and Takeda to improve post-transplant care through medical education for healthcare professionals.

This screenshot shows the 'Patient advocacy and awareness' article on the ESOT website. The article features a quote: "A life that is gained should also be lived". It details the project My Life My Health (MLMH) and its objectives: supporting patient literacy, the adaptation process, raising healthcare professionals' awareness, and empowering transplant recipients. A section titled 'Activities' lists two items: 'My Life My Health toolkit box' with a 'View >' button, and 'Supporting coherence and adaptation after transplantation' with a 'Watch on Transplant Live >' button. A blue arrow points from this button to the video player in the adjacent screenshot.

The video player interface shows a navigation menu with 'INTRODUCTION', 'LECTURES', 'EVALUATION SURVEY', and 'SUPPORTERS'. Under 'LECTURES', 'Lecture 1' is selected. The video title is 'Person-centred communication and care' by Anna Forsberg, Lund University, Sweden. The 'Introduction' text states: "This lecture by Professor Anna Forsberg discusses the essentials of person-centred communication and care. The adaptation process after transplantation is explored and key steps in person-centred communication are presented. Further, the lecture includes strategies to achieve precision in transplant care and communication and it outlines the key parts of a person-centred health plan." A quote from Anna Forsberg is displayed on the right. The video player shows a thumbnail with the text 'ESOT TRANSPLANT LIVE ONLINE EDUCATION' and a play button. A blue arrow points from the 'Watch on Transplant Live >' button in the previous screenshot to this video player.

# The Life-Balance Puzzle

## What challenges do you need assistance with?

Different aspects of life are affected at different times for those living with a long-term illness.

Use the puzzle to identify which areas you need to prioritize right now. Go through the pieces together and select up to three areas that require support and change. Also, choose three areas where you need to collectively think.



I am confident that I can handle this in my everyday life and I know how to reach out for support. I need assistance.



I can manage this if I am given advice and some support on how to start.



I do not know how to manage this part of my everyday life. I need assistance.





# The health plan

1. This is how I want to feel. This is the performance level I wish to achieve.
2. These are the efforts I can make on my own. These are my useful coping strategies.
3. These are the areas in my everyday life where I need assistance from the transplant unit or other health care professionals.

# WORKSHOP IN LONDON

*September 2024*



# Guy's hospital





## Multiprofessional workshop



# Mi vida- mi salud

Barcelona,

November 2024

# Mi vida, mi salud

Usted recibe esta información del equipo de trasplante por haber sido trasplantado

Esta es una guía de atención centrada en la persona que se focaliza en la vida de la persona como receptora de un trasplante.

## El puzzle del equilibrio vital

¿Con qué retos necesita ayuda?

 Conocimientos sobre mi enfermedad	 Sentimientos y toma de conciencia	 Finanzas/aspectos económicos	 Familiares, amigos y red social
 Tareas del hogar	 Relaciones íntimas, sexualidad	 Cuidado personal	 Desplazamientos de la vida diaria o en el tiempo libre
 Síntomas y efectos secundarios	 Actividades diarias y trabajo	 Actividades en el tiempo libre	 Participación en el cuidado de la salud
 Estilo de vida	 Consejos de profesionales de la salud	 Participación en organizaciones de pacientes	 ?

Para quienes viven con una enfermedad prolongada, diferentes aspectos de la vida se ven afectados a lo largo de esta.

- Sé que puedo gestionar esto en mi vida diaria y sé cómo buscar apoyo.
- Puedo lograrlo si me dan consejos y algo de apoyo sobre cómo empezar.

...esta parte de mi vida cotidiana.

## Atención centrada en la persona trasplantada

Esta es una guía de atención centrada en la persona que se focaliza en la vida de la persona como receptora de un trasplante.

Este documento se desarrolló en colaboración con Anna Forsberg, enfermera y profesora universitaria, especializada en el trasplante de órganos. Trabaja en la Universidad de Lund y en el Hospital Universitario de Skåne.

# The Spanish materials

### The Life-Balance Puzzle

What challenges do you need assistance with?

Different aspects of life are affected at different times for those living with a long term illness. Use the puzzle to identify which areas you need to prioritise right now. Go through the pieces together and collect up to three areas that require support and change. Also, choose three areas where you need to collectively think.

- 1. You consider that you have done as much as you can and now you need help for certain life areas.
- 2. You struggle to fit in your illness and your support with life.
- 3. You need help to fit in with your life, I need assistance.

### The Life-Balance Puzzle

What challenges do you need assistance with?

Different aspects of life are affected at different times for those living with a long term illness. Use the puzzle to identify which areas you need to prioritise right now. Go through the pieces together and collect up to three areas that require support and change. Also, choose three areas where you need to collectively think.

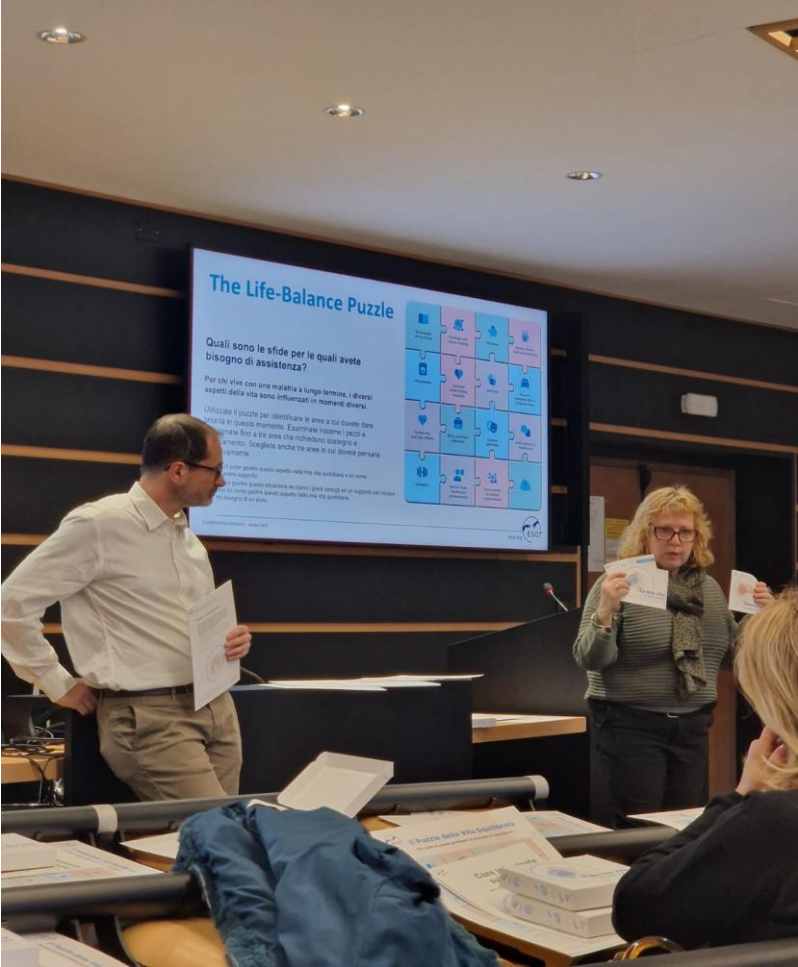
- 1. You consider that you have done as much as you can and now you need help for certain life areas.
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- 3. You need help to fit in with your life, I need assistance.



An historical event



# Bologna- Sant' Orsola Hospital



March 2025

## Conclusion so far

- **Person centred care is a powerful method regardless of where you are in the world.**
- **Nurses are strengthened in their autonomy by useful tools.**
- **Patients feel empowered by person centred tools.**
- **The need to be taken seriously is generic and a human basic need regardless of country.**
- **Nurses can make a difference as first line professionals.**

# Where can I find the materials?

You can download the materials from the ESOT Website

The image displays three overlapping screenshots of the ESOT website. The leftmost screenshot shows the 'Enhancing post-transplant care' section with a 'Learn more' button. The middle screenshot shows the 'Patient advocacy and awareness' section with a 'View' button. The rightmost screenshot shows the 'Italiano' language selection button and a grid of materials including 'La mia vita - La mia salute' (The Box, Booklet, Workbook, Being Related, The Poster) and 'Cure incentrate sulla persona' (The Brochure). A blue arrow points from the 'Patient advocacy and awareness' section to the 'Italiano' button.



# Questions

Or Comments



**Thank you**