



**Mater Misericordiae University Hospital (MMUH)**

# **LUNG TRANSPLANT**

## **Patient Information Booklet**

**06/07/2019**

## Section 1: Introduction - My transplant information

### My Transplant Information

Name:

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Family and friends who will support me:

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Transplant Co-ordinators:

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Team members I have met:

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## Hospital Information

### Address

Mater Misericordiae University Hospital,  
Eccles Street,  
Dublin D07 R2WY,  
Ireland.  
Telephone number: 01 803 2000  
[www.mater.ie](http://www.mater.ie)

### Amenities

Paid parking is available in a 24-hour underground car park. The entrance is on Eccles Street.

There are four coffee shops in the hospital.

### Visiting times

2.00pm - 4.00pm and 6.30pm - 8.00pm every day.

### Accommodation

There are some hostel beds available on site for relatives of patients. However, due to the demand, these places are limited.  
There is a nightly charge for staying in the hostel.

We will, though, do our best to accommodate you. If your stay is prolonged, contact the Clinical Nurse Manager in your area to enquire about hostel accommodation.

### Useful Contact Numbers

Hospital Switchboard	01 803 2000
Intensive Care	01 803 2356 and 01 803 2777
Coronary Care Unit	01 803 4700
Sacred Heart Ward	01 803 4760
St. Cecelia's Ward	01 803 2740
Cardiothoracic High Dependency Unit	01 803 4532
Heart Lung Transplant Ward	01 803 4237
Transplant Medical Social Worker	01 803 2406/2267

Transplant Physiotherapist	Contact through the switchboard
Post Heart Transplant Nurse Specialist	01 803 2660
Post Lung Transplant Nurse Specialist	01 803 4296
Heart and Lung Transplant Co-ordinators	01 803 2986/4274/4747/5447/2984
Out of hours	Contact the switchboard

## **Patient Support Association Contact Details**

### **Irish Heart and Lung Transplant Association (IHLTA)**

Tel: 087 4128612  
Email: [info@ihlta.ie](mailto:info@ihlta.ie)  
[www.ihlta.com](http://www.ihlta.com)

### **Irish Lung Fibrosis Association (ILFA)**

Tel: 01 2985336  
[www.ilfa.ie](http://www.ilfa.ie)

### **Cystic Fibrosis Association of Ireland**

CF House, 24 Rathmines Road, Dublin 6  
Tel: 01 4962433  
[www.cfireland.ie](http://www.cfireland.ie)

### **Alpha One Foundation**

Alpha One Suite, RCSI Building, Beaumont Hospital, Dublin 9  
Tel: 01 8093871  
[www.alpha1.ie](http://www.alpha1.ie)

### **The Carers Association**

[www.carersireland.com](http://www.carersireland.com)  
Freephone 1800240724

## **Useful Links**

<http://www.hse.ie/eng/about/Who/organdonation/>  
[www.hse.ie](http://www.hse.ie)  
[www.citizensinformation.ie](http://www.citizensinformation.ie)

## Glossary of Terms

**Heart transplant:** an operation where your heart is removed and is replaced with a donated heart. You will be on a heart-lung bypass machine during this surgery.

**Lung transplant:** an operation where one or both of your lungs are removed and replaced with a lung(s) from a donor. You may need to be placed on a heart-lung bypass machine during this surgery.

**Medical Social Worker (MSW):** a professional who provides supportive counselling for patients and their family before and after transplant. The medical social worker meets with all transplant candidates and their families to assess their situation and family supports, and ensure a plan for post-transplant care is in place.

**Transplant centre:** in Ireland, the Mater Misericordiae University Hospital (MMUH) is the Heart and Lung transplant centre.

**Transplant clinic:** an outpatient clinic where patients who have had a transplant have check-ups and are monitored by members of the transplant team.

**Transplant conference:** a meeting of the transplant team to discuss a person's evaluation results to see if the person is suitable for transplant.

**Transplant Co-ordinator:** a registered nurse who provides pre-transplant information, co-ordinates the transplant evaluation process as well as coordinating all activities on the night of transplant. The transplant co-ordinator is a point of contact for patients while they are on the waiting list.

**Transplant Nurse Specialist/Clinical Nurse Specialist:** a registered nurse who has specialised training and experience in the care of patients after transplant.

**Transplant Psychologist:** a registered psychologist who provides psychological support and intervention tailored to the needs of transplant patients. The psychologist is trained in mental health but also specialises in helping people cope with and adjust to times of stress and transition.

**Transplant programme:** the national system for organising organ transplants. The transplant centre, the donor register, the medical professionals and administrators are all part of the overall programme.

**Transplant multidisciplinary team:** all the hospital staff who are involved in a transplant patient's care – for example, doctors, surgeons, anaesthetists, nurses, physiotherapists, co-ordinators, medical social workers, and so on.

## Contributors

This booklet was put together by members of our transplant team. It is an important resource for you and your caregivers. We hope that you find it helpful, and we would also like to hear any suggestions you might have to improve the booklet in the future.

## Introduction

Lung transplant is offered to patients who have severe lung disease for which other treatment options are no longer adequate. The two reasons for considering lung transplant are:

- to improve survival from lung disease, and
- to improve the quality of life for people with advanced lung disease.

In May 2005, the first lung transplant procedure undertaken in the State took place in the MMUH, this was closely followed by the first double lung transplant in 2006. The heart transplant programme in the MMUH began in September 1985 and the hospital is the National Heart and Lung Transplant Centre.

We hope that this information booklet will help your understanding of lung transplant and give you some of the information that you will need in order to work with us towards a good outcome. The purpose of this information booklet is to explain what is involved in having a lung transplant at the MMUH.

### **The booklet is divided into three parts:**

1. Before the transplant
2. The transplant operation itself
3. Life after transplant

Many patients are concerned when lung transplantation is first mentioned to them, but it is important to think about this decision carefully and for us to have time to fully understand your medical, psychological and social situation. We feel that it is important for you to have a thorough understanding of both the transplant assessment process and the transplantation process itself, and to have realistic expectations of the outcome.

To achieve the best outcome, it is important that you establish good communication with the team so that we can support you in the best way possible.

There will be a large team involved in your care, before, during and after transplantation. During your meetings with transplant physicians, surgeons, nurse specialist, physiotherapist and social workers, you will have opportunities to ask questions about the transplant process. At first, it can feel overwhelming. However, every meeting with a team member is an opportunity for you to better understand transplantation. Also, it is a good idea to bring a family member or friend with you for support so that you have someone to talk things over with.

The transplantation team at the National Heart and Lung Transplantation programme at the Mater Misericordiae University Hospital (MMUH) is here to support you throughout the process of transplantation. We encourage you to ask questions and engage with us. We will do whatever we can to ensure you have the best possible outcome.

## **Foreword by Mr. Lars Nolke and Prof. Jim Egan**

The booklet has been prepared by the transplant team, and it is designed for patients and their families undergoing lung transplant assessment.

It is compulsory for you and your supports to read this booklet, as it gives you clear information about what a transplant is and what it will mean for you and your family. It also explains what we expect from you and from your family.

Every patient's situation is unique, and the information here is a guide only. It complements but cannot replace the information given to you by the transplant team.

We understand that you will receive a lot of information during your assessment, and you may feel overwhelmed and anxious. Our medical and nursing staff will support you throughout the process.

**Please keep this booklet safely, as you will need it as you prepare for your transplant. You will also need it for reference afterwards.**



## Your Responsibilities

A transplant is a major operation and, therefore, it has risks. A transplant can be an effective treatment for certain lung conditions, but it is not a 'cure'. For many people, a transplant can improve their quality of life and also extend it.

After you have had your transplant, you will have to take immunosuppressive (anti-rejection) medication every day for the rest of your life. This medication helps to prevent your body from rejecting your new lung or lungs.

**Keeping yourself and your new lung or lungs healthy is a team effort – and you are the key part of that team.**

The team consists of you, your family, nurses, doctors, and other members of the hospital staff. It is important that you follow the guidelines in relation to lifestyle advice.

## What do I need to do?

As a potential transplant recipient, you are the most important caretaker of your health and the transplanted organ. In order for you to have the best outcome, we expect you to:

### Get informed!

- be involved, to the best of your ability, with your assessment and treatment, and take on board the recommendations made by all members of the transplant team.

### Keep us informed!

- keep in regular contact with the transplant team, and attend all of your appointments.
- Tell us if there are any changes in your health, or symptoms.
- keep accurate healthcare records – know and record your medications, any changes in your treatment and any tests you have had done.
- tell us if you or your care team are having any difficulties coping.
- respect the need for confidentiality for yourself and other patients.

## Get support!

- have a support person who is able to help with your care needs, including bringing you to appointments. You must inform us if there is any change in your support person's circumstances.
- work in partnership with the team in a respectful, co-operative and courteous manner.

## Keep moving!

- maintain a healthy lifestyle, and make any lifestyle, dietary or exercise changes recommended by the transplant team.
- follow the instructions given by the team for your exercise programme.
- you will be expected to do pulmonary rehab or an approved exercise programme to ensure that you are fit enough for transplant.



## Section 2: Before transplant

### Transplant Assessment

***I have been referred to the MMUH for a transplant assessment.***

***What is involved?***

Your assessment may be done as an inpatient in the MMUH, or an outpatient at your referring hospital. An assessment may last for a number of weeks; however it can occasionally take longer. This usually depends on your underlying condition. If we need to do further tests, you may have to stay in hospital, or you may need to come back as an outpatient, or be re-admitted.

During the assessment, you will have a variety of tests and investigations carried out. The results are discussed at the transplant conference by a team of transplant experts and they will decide if you are suitable for a transplant or if a transplant would be too risky for you.

Not all patients having assessments will be suitable for transplant. If we decide that transplant is not the best option for you, we will tell you that, and suggest alternative treatments if possible.

You might have been discharged from hospital before the result of the assessment is discussed by the team. If you are not given a decision on your transplant suitability before you go home, the transplant co-ordinator (or another member of the team) will contact you with the decision when your case has been discussed at the transplant conference.

Throughout your assessment, members of the medical and nursing staff will make sure that you have a chance to discuss the contents of this booklet. The information enables you to go through the various stages of the pre and post-transplant processes, and it will help you to make an informed decision regarding transplantation. It is you and your family's opportunity to discuss any concerns you have about the process.

**The transplant team consists of:**

- transplant surgeons;
- transplant physicians;
- anaesthetists and critical care team;
- post-transplant nurses;
- transplant co-ordinators;
- nursing staff;
- doctors;
- social worker;
- physiotherapist;
- pharmacist;
- dietician;
- psychologist/psychiatrist;
- speech and language therapist.

During the assessment, you will meet the dietician who will advise you on a diet that is nutritionally balanced for your needs. This will help your recovery after surgery. It is important that you stay within a healthy weight range for transplant. You will also meet a physiotherapist who will assess your condition and give you advice about activity and exercise. You may be advised to attend pulmonary rehabilitation (special exercise classes) to get fit enough for transplant.

Before you can go on the transplant list, a family meeting will be held during your stay or before you are listed. This is to make sure that everyone is very clear about what is involved in the assessment process, what life on the active transplant list is like, and what to expect when there is a donor offer. This is usually led by the medical social worker.

You may be asked to meet a target weight or go to exercise or rehabilitation classes before being made “active” on the transplant list.

The medical and nursing team will explain all the tests you are having, and support you throughout the assessment process. Transplant is an operation with serious risks – therefore, a thorough physical, psychological and social lifestyle assessment is carried out. This is to make sure that the right decision is made for you.

If you are accepted on to the transplant waiting list, you will be reviewed regularly by the medical or nursing team in MMUH or in your local hospital. If your condition deteriorates, or other issues arise, such as kidney problems, you may need further treatment to make you fit for the transplant. If a change in your medical condition affects the chance of a transplant being successful, you may be taken off the list either temporarily or permanently.



*The transplant team celebrate ten years of lung transplant in the MMUH*

The period of time during which a successful transplant can take place is sometimes called a 'transplant window'. After that length of time, you may become too ill to have the operation.

Before you are discharged after your assessment, you should know what follow-up arrangements are made for you and who to contact if you have any problems or queries.

## **The Waiting List**

An up-to-date list of all patients waiting for transplants is kept by the transplant co-ordinators. We don't know how long you will have to wait for a lung that matches your blood group, type and size. When you are called for transplant is determined by suitable organs becoming available and **not** how long you have been on the transplant waiting list. We select recipients mainly based on blood group, size (height and weight), results of antibody tests, tissue typing, and your clinical condition.

Once you are placed on the transplant list, it could take from days to months or even years for the right organ to come along for you. During this waiting period, your condition will be reviewed by your local hospital and the MMUH transplant team. Your referring doctor will still be responsible for your care during this period. If your condition changes, a new treatment is started, or if you deteriorate between your visits, you and your referring doctor should keep us informed. (See “Keep us informed” above)

There is no guarantee that suitable organs will become available in time for everybody on the transplant list.

***It is very important to keep the Mater team up to date with any changes in your condition or medications while you are waiting for a transplant.***

## **Coping with life on the Waiting List**

Waiting for a transplant can be a time of great emotional and practical upheaval, and many patients have worries and concerns. Patients cope with life on the waiting list in very different ways, some of which can make this time easier for you and your family.

### **Here are some points that may help:**

- Make plans about being called for a transplant from the day you are put on the waiting list. It is never too soon to prepare.
- Keep a bag packed and make plans with your family about who will accompany you to the hospital. When you go on the waiting list, the transplant co-ordinator will discuss the travel details with you for when you get the call to come in.
- Remember that, even though you are now on the waiting list, your life should go on as normal. Make sure that your usual daily activities continue but make sure that you are always contactable.
- Take time to think about what a transplant means to you, and how you and your family will cope afterwards. If you think you'll need help afterwards, make a plan for that before your operation.
- **We recommend that you totally avoid drinking alcohol while on the waiting list as you may be called for transplant at any time.**

**While you are on the waiting list, we ask that you keep the transplant coordinator up to date on the following:**

- your contact information and the contact information of your next of kin.
- if you are admitted to another hospital.
- if there are any changes to your treatment or medication.
- any changes to your weight.
- the address and contact details of where you are staying. If you plan on being away at any stage let us know the address and contact details of where you will be staying.

## **Practical and Psychological Support**

### ***Medical Social Work (MSW) Assessment***

The medical social worker (MSW) is part of the transplant team and provides pre- and post-transplant care. The MSW work closely with other team members to make sure you have the best possible outcome.

Their role includes:

- assessment as part of the initial transplant work-up period.
- providing emotional support.
- education on the impact of transplant on yourself and your family.
- information on practical issues.
- referrals to other agencies if necessary.

You will meet the MSW as part of the transplant assessment process to explore your support needs before and after your transplant. As part of this assessment, the MSW will ask to meet with the family members or friends you identify as your main supports to discuss what will be expected of them. You need to have a good, consistent and reliable network of psychological and practical supports in place in order to be considered for transplant and to have the best outcome after your transplant.

If you are on the active transplant waiting list, or you have had your transplant, please feel free to contact the MSW if you have any questions or support needs.

## Palliative Care

We may refer you to the palliative care service to help with managing your symptoms for example breathlessness or pain.

## Your Primary Carers

**Our experience of transplant is that having a strong network of carers and support is an essential part of good transplant outcomes, and will help you to get back to independent living as soon as possible.**

We also know that in the first few months after the surgery, every transplant patient will need practical and emotional support with many aspects of their day-to-day living. Some people may require support from time to time; others might need support on a longer-term basis.

As part of the MSW assessment, you will be asked to identify your primary carers or 'care team' – that is, family, friends or people who will support you while you are on the active transplant list and, more particularly, after your transplant as the need arises. It is important to speak with family and friends about who can realistically provide care to you on an on-going lifelong basis. You will be required to complete a 'Contract of Care for Transplant' to identify your carers for transplant and provide their names, contact details and availability.

***Your carers will have an important role in ensuring that your transplant outcome is good. This is a big commitment from your carers.***

**Some of the supports needed from carers include, but are not limited to:**

- practical support if you are called in for transplant, and continuing that support if the transplant does not go ahead.
- providing emotional support and friendship on an ongoing basis.
- being available for learning and advice sessions from different members of the team in the hospital before you come home after your transplant.
- attending family meetings as necessary.
- making sure your home is cleaned thoroughly before you come home, and providing assistance with cooking, collecting medications, day-to-day tasks and any other practical jobs that need to be done.



- transporting you to and from transplant clinic appointments in the MMUH
  - Initially, you will need to attend post-transplant clinics every week until the post-transplant team say otherwise. In the first few months after your transplant, you **won't** be able to use public transport, so you will need to make sure someone can drive you to your appointment on time and bring you home again. We recommend that you do not drive for three months after transplant. Your post-transplant nurse will tell you when you can start using public transport or drive again.
- being available to you for emergency and unscheduled appointments and care needs on an ongoing basis for the rest of your life.
- contacting the transplant team if any concerns arise.

We are aware of the significant impact and stresses that caring for someone before or after a transplant can place on family or carers. Therefore, it is very important that carers also take care of themselves by looking after their own physical and mental health. There are various support groups that may be of benefit to both patients and carers. Details of these groups are included in this book.

Please speak with the medical social worker or a member of the transplant team if you have any further questions about any of the above.

## **Preparing for Transplant with your Carers**

If you are suitable for transplant, you will be placed on the active waiting list. It is normal to feel a little anxious or 'jumpy' when the phone rings during the first few weeks after being placed on the list, but this usually lessens as time passes. It is essential to continue with your normal life and maintain a good routine during this time as much as you are able. It is impossible to know when you may be called for transplant.

To help yourself prepare as much as you can for transplant, you and your carers should consider addressing the following areas:

- Emotional
- Medical
- Educational (in relation to transplant)
- Financial
- Spiritual
- Practical

## Emotional Impact of Transplant Assessment

The time immediately after the transplant assessment is often an emotionally and physically draining time for patients and families who are eager to know the outcome of the assessment.

**Here are some tips that might help you to cope with this waiting period:**

- Try not to put a specific timeframe on knowing the outcome of the assessment, as this may lead to increased frustration and anxiety. If you have queries, speak with the team or transplant co-ordinators.
- As the transplant assessment process is very detailed, you will have many tests and meet many health professionals. If it helps, use this booklet to record names and useful information.
- Remember that not everyone will be suitable for transplant, however if you are not suitable, you will be followed up by your referring team. If you are told you are not suitable, this can be a huge disappointment for you and your family and friends. It is normal to feel upset, anxious or down. However if this low mood continues, please speak with your GP who may be able to recommend local services to help you (for example, counselling services). We will contact your GP and referring consultant to let them know about the outcome of the assessment.

## Emotional Preparation

Being anxious when you are ill is normal, and how you deal with your illness or transplant is very personal to you. The transplant process can be a very emotional time for patients and their families and friends. Some people may be more stressed before the transplant, while others may be more stressed afterwards as they learn to cope with changes in their lifestyle.

Different people will have different ways of dealing with or expressing their emotions. The emotional changes and feelings you might experience include:

- Feeling sad, angry, frustrated, anxious or overwhelmed.
- Feeling like you have lost control.
- Crying frequently or easily.
- Feeling numb.
- Being unable to focus or concentrate.

- Being irritable.
- Having changes in your sleeping pattern and appetite.
- Having mood changes.
- Being reluctant to go out or take part in social activities.
- Being aware of changes in relationships.

If you or your family or carers notice any significant or prolonged changes in your mood, you should speak with a member of the transplant team. Psychological support and counselling is available from the Medical Social Worker or Psychologist working on the team. Talking with a professional about your mood or how you are coping is increasingly acknowledged as a 'normal' part of the transplant experience. This is because we know that many patients will experience difficulties at some point along the way.

### **Difficulties that the psychologist often works with include:**

- Low mood.
- Feelings of anxiety.
- Emotional adjustment.
- Panic attacks.
- Loss/ bereavement.
- Relationship issues.
- Body image concerns.
- Sexual issues.
- Phobias (e.g. claustrophobia and needle phobia).
- If you feel it may be of benefit to speak to either the MSW or a Psychologist, please discuss this with someone from the transplant team who can arrange a referral. During the first visit the treatment plan will be explained including issues of confidentiality. A plan will be made collaboratively based on your needs and wishes. You may meet for just one or two sessions or for longer term input depending on your needs.



## Medical

While on the active list for transplant, it is important to remain as healthy and as active as you can. Look after your physical and mental wellbeing as recommended by the transplant team.

***Be organised*** – write down your medications, appointments, results, contact numbers, and so on in a notebook and make sure that your carers know where this information is.

## Educational

For many patients and their families or carers, transplant is a new world that involves ongoing education and life-long learning for everyone involved. This booklet is part of the educational process, and you will receive ongoing relevant information from the different transplant team members.

If you or your care team have questions in relation to transplant, it is important to ask the transplant team. We know that there is a lot of relevant and good information about transplant on the internet, but please be aware that it is easy to get incorrect or misleading information that is not relevant to your condition.

Some people find it useful to join a suitable support group. Through group learning, you gain more knowledge and insight into your condition which can help you feel more in control about the experience and what to expect. Please ask us for details.

If you have children or grandchildren, only you can decide when it is the right time to tell them about your transplant. When the time is right, tell them in simple language that they can understand, whatever their age. Check-in regularly with children and teenagers to see if they have questions, and be wary of them looking for information on the internet. There are various books available to help in explaining illness to children. Ask your medical social worker for recommended names.

## **Financial Planning**

Being sick and having a transplant can put an enormous financial strain on patients and their families, which can cause anxiety and worry. It is important, therefore, to know about any assistance that may be available to you. Unexpected expenses can arise for anybody, so try to plan your finances with your family or carers as best you can.

### **Useful sources of information or assistance with financial planning include:**

- Community welfare officer in your local health centre
- Citizens advice centres - phone the Citizens Information phone service on 0761 07 4000 (Monday to Friday, 9am to 8pm) or online at [www.citizensinformation.ie](http://www.citizensinformation.ie)
- MABS Centre – phone The MABS Helpline 0761 07 2000, Monday to Friday from 9am to 8pm for information over the phone, or online at [www.mabs.ie](http://www.mabs.ie)

Here are some frequently asked questions that arise about financial issues. The answers might help you with your financial planning. Please note that the information in the answers is correct at the time of writing, but it could change over time.

Remember that it is absolutely essential to comply with post-transplant care as an essential part of your ongoing medical management. Therefore, take that into account in your financial planning. If you have questions about your ability to return to work after your transplant, please speak with the transplant doctors. You can also speak with the MSW if you have specific queries, or you want further information about specific financial issues.

***Q: Am I entitled to social welfare?***

A: Social welfare is assessed on an individual basis and you should contact your Community Welfare Officer in your local health centre for further information. More information about the different types of social welfare payments is at [www.citizensinformation.ie](http://www.citizensinformation.ie)

***Q: How will I pay my hospital bills?***

A: This will depend on your personal circumstances. If you have a medical card, this will cover the cost of your hospital stay. However, please contact the Patient Accounts Department in the hospital to check this or if you have further queries.

If you have private health insurance, please contact your insurer and they will advise you of your level of cover.

If you have neither a medical card nor private insurance, normal hospital charges will apply. You should discuss this with the transplant team during your assessment. More information about hospital charges is available on [www.hse.ie](http://www.hse.ie)

***Q: Am I entitled to a medical card?***

A: Having a transplant does not automatically entitle you to a medical card. Entitlement to a medical card is assessed on an individual basis. More information about applying for a medical card, the financial assessment and application forms are available at [www.hse.ie](http://www.hse.ie)

***Q: How will I pay for my medications?***

A: This will depend on your personal circumstances. If you have a medical card, this will cover the cost of many of your medications. It is important to remember the medications covered by the medical card may change, so please speak with your local pharmacist about this.

You are entitled to a Drugs Payment Scheme (DPS) card which will cap the

monthly amount you (and your family) spend on medications. This is currently around €140 per month. You can get the DPS application form from your local pharmacist, and more information is available online at [www.citizensinformation.ie](http://www.citizensinformation.ie)

***Q: If I need care before or after transplant, will my carer be entitled to carer's allowance?***

A: Carer's Allowance is assessed individually based on care needs. You and your carer will need to apply to the Department of Social Protection by completing the Carer's Allowance application form. This form will also need to be completed by your GP. Application forms are available at your local health centre, local citizens information centre or online at [www.citizensinformation.ie](http://www.citizensinformation.ie)

***Q: Is there assistance with travel, parking or accommodation costs for my family and carers while I am in hospital?***

A: No there is not. There is limited, low-cost accommodation available in the hostel building on site and some local hotels and B&Bs offer special 'hospital' rates. You can also speak with the Community Welfare Officer in your local health centre to see if there is any financial assistance they can provide.

***Q: Is there financial assistance available towards the cost of travel to post-transplant appointments?***

A: No there is not. We advise you to speak with the Community Welfare Officer in your local health centre to see if there is any financial assistance they can provide.

## **Spiritual**

For some patients, transplantation may be spiritually challenging. Being ill and waiting for a transplant may strengthen some people's faith; for others, it may call it into question. Knowing that another person died and their family gave a recipient the gift of their loved one's organ may raise spiritual questions for you. For others, it won't. Just as different patients have different medical issues, spiritual issues – if there are any – differ from person to person too.

If you have spiritual requests, concerns or questions, please tell your carer, speak with a member of your faith, or ask the staff to put you in touch with the pastoral care team in the hospital.

## End-of-Life Care

Sadly, some people may not be suitable for transplant or may not get a transplant in time. It may be useful to speak with your GP or Respiratory Team about the role of Palliative Care and if referral to their services is right for you. Discussing your wishes with your family, 'getting your affairs in order', and making a will can be frightening and daunting and it is good to seek support from your family or friends if needed. In the event of death, a post-mortem may be legally required or suggested by your medical team in order to better understand your medical condition or to contribute to knowledge or research in the area. If you need support or information about this, please discuss this with your team or GP; the Irish Hospice Foundation also has information that may be of use at <https://hospicefoundation.ie/programmes/public-awareness/think-ahead/>





## Practical Tips while Waiting for Transplant

During the transplant assessment process, you will have received information from different members of the team about preparing yourself for transplant. You will have identified your primary carers during the assessment with the MSW, and it is important that you and your carers work together to plan for practical issues that may arise before, during or after your transplant.

Here are some tips to help you deal with the practical things that can help to reduce stress and make things run smoothly.

### Practical tips to Prepare for Transplant

- Have your bags packed so you are ready to go when you get the call for transplant. Make sure you have sufficient medications, particularly oxygen (if needed) and transport home in case the transplant does not go ahead.
- Make sure your family and carers have contact numbers or email addresses for people they may need to contact during or after the transplant.
- Organise your personal affairs. For example, make a will, allow others to access your bank accounts or pay your bills while you're in hospital.
- If you receive any social welfare payments, you may wish to appoint someone else to collect it on your behalf or request that it is paid directly into your account.
- Organise childcare in advance if you need to. For example, set up a list of friends or family who can drop children to school, make dinners, and so on.
- If you have pets, speak with the transplant team during the assessment process about managing pets in the home after your transplant. Also, make arrangements for their care while you're in hospital.

## Section 3: Getting the Call for Transplant: What happens next?

### What happens when there is a donor offer?

The transplant co-ordinator will need to get you to the hospital safely and in the shortest possible time. They will arrange an ambulance to collect you.

**When you get the news that there is a donor offer, there are some important things to remember:**

- Do not eat or drink from the time of the call.
- Contact your family/care team to let them know what is happening.
- Bring your current medication and a list of the doses you take with you.
- Bring your bag containing essential items such as night clothes, slippers, **and this booklet!** Once you go on the transplant waiting list, have this bag packed and ready.
- On a practical note, you will need larger sized footwear and clothes for after transplant as your feet, legs and body can be swollen after the operation. Tops with buttons are the most practical, and sturdy footwear is essential.
- The hospital will not be responsible for any loss or damage to personal items – therefore do not bring any valuables with you.
- Plan for the fact that the transplant may not happen – for example, you will need someone to take you home again, and, if you are on oxygen, make sure you have enough portable oxygen to get you home.

Before we know if the transplant is going ahead, a full pre-operative surgical exam will be carried out on you when you arrive at the Mater Hospital. Also, a doctor will discuss the operation with you and then ask you to sign your consent form for the transplant.

You may also see an anaesthetist before knowing if the transplant is going ahead. You will be started on immunosuppression (anti-rejection) medication before going to the operating theatre.

These procedures are done before the decision about the transplant is made. This is done to save time. When the decision is made that the transplant is going ahead for you, we need to proceed without delay.

Please note that there may be other patients brought to the Mater Hospital at the same time as you as potential recipients for the same donor offer.

## **Cancellation of the Transplant**

We only want to give you a lung or lungs which have a high chance of functioning well for you. The decision to transplant is based on blood group, size, the condition of the lungs and immune factors.

Sometimes we have to cancel a transplant. Although it doesn't happen often, you may even have been given an anaesthetic by this time.

**There are many reasons why a transplant may not happen and they include:**

- when the organs are unsuitable.
- your cross-match blood test shows that you have incompatible antibodies.
- the donor organ may be more suitable for another recipient.
- the surgeon decides you are not well enough to undergo a transplant at this time - for example, you might have a high temperature or very abnormal blood results.

Although we understand that it is extremely distressing and disappointing, we will have to cancel the transplant if any of the above occurs. You and your family should prepare yourselves for this happening. If this happens, you will need to make your own arrangements to go home.

## **The Transplant Operation**

The transplant operation is complex, and a large team of skilled professionals will be looking after you in theatre. There are many different roles involving several different surgeons, anaesthetists, nurses, doctors and perfusionists (perfusionists manage the heart-lung bypass machine).

You may be in theatre for up to ten hours or even longer, depending on the type of surgery and your underlying condition.

The co-ordinators will keep your next of kin informed during the surgery unless you ask them not to. Usually, a member of the surgical team will speak to your family after the surgery.

## **The Intensive Care Unit (ICU)**

Immediately after your surgery, you will be taken to the intensive care unit (ICU) to recover, where a team of specially trained staff will take care of you. Their goal is to help you recover as quickly and safely as possible. Among all the staff caring for you, there will be one nurse who is assigned just for you.

The ICU is a very busy environment and you can expect bright lights and a great deal of activity during the day. For your safety, there is CCTV in all patient rooms. Live images are relayed to the nurses' station but are not recorded. Many of the sounds you will hear will be from monitors and equipment, but do not be frightened as you are in expert hands.

## **Breathing**

To help you breathe, a breathing tube will be inserted while you are asleep in theatre. This tube will be connected to a ventilator to help with your breathing immediately after your surgery. As you will not be able to talk or swallow while this tube is in place, your nurse will anticipate your needs and ask you questions that require only a 'yes' or 'no' answer. When you are fully awake, the breathing tube will be removed, this process can take several hours and it can be uncomfortable. Your throat can take a while to recover so you won't be able to talk immediately.

## **Nutrition**

You will not be able to eat or drink while you have the breathing tube in place and are on the ventilator. There may be another tube through your nose, which empties the acid from your stomach until you are able to eat and drink again. This

tube is called a 'nasogastric' tube. If it is a long time before you can begin eating and drinking again, you can be fed through your nasogastric tube. Usually, it will be removed a few days after the surgery after it is decided that you are ready to eat and drink again.

## **Monitoring and equipment**

You will be attached to a heart and blood pressure monitor, and there will be drips in the veins of your arms and neck that will give you fluids and medication. There will also be tubes in your chest, draining fluid that may have collected there. These tubes will restrict your movement, but they will be removed within a few days of surgery. You will have a urinary catheter in place that will drain urine from your bladder continuously.

You will have a scar (a wound) which may be a 'sternotomy' (down the length of the breastbone), a 'clam shell' (below the ribs) or 'thoracotomy' (one side of the ribs). The scar will be covered with a dressing. The stitches don't need to be removed as they dissolve over time.

## **Pain relief**

You may be worried that you'll be in pain after your surgery. It might help you to know that patients who have had transplants have said that the pain is not as severe as they thought it would be.

To control your pain, you will be given pain relief, which will be given intravenously (in a drip), orally (by mouth) or by an epidural. An epidural involves a small tube inserted into your back by an anaesthetist. This tube delivers medicine which will block pain to the area around your scar. You may also be prescribed patches that contain pain killers.

It is worth knowing that most patients who have spent time in ICU do not remember much about this initial period after surgery. This is due to the medication given to keep them asleep and free from pain. Some patients have reported hallucinations. These are not unusual and should reduce over time. You may want to talk to someone if this happens to you. Tell your ICU nurse or any member of the team.

Some people experience delirium while in intensive care. Delirium could cause you to be either aggressive and agitated, or sleepy and inactive – or sometimes a mix of both. It could be very distressing for you or for your relatives. This problem can have more than one cause and can need several treatments.

The usual stay in the ICU is 3 - 5 days, but it will depend on your condition. After ICU, you will continue your post-operative care in a high-dependency area, usually the Cardiothoracic High-Dependency Unit (CTHDU). You can expect to be in hospital for a total of 10 - 14 days. This may vary, though, depending on your condition.

## Physiotherapy

The physiotherapist will see you in ICU. Physiotherapy is a vital part of your care, and this will start from day one in the ICU. It will involve breathing exercises to help clear any sputum from your lungs, and getting you out of bed as soon as possible. As you make progress, you will be encouraged to become more active and mobile.

## Visitors

In ICU, visitors are limited to immediate next of kin and you may only have two visitors at a time. The visiting hours are 2pm - 4pm and 6.30pm - 8pm. The staff will ask your visitors to wash their hands on entering and leaving the unit. It is helpful to have one key person who will tell the rest of your family and friends about your progress to avoid you and the nursing staff being disturbed by frequent telephone calls. Our priority is looking after you.

**You should only have visits from next of kin or your chosen carers while in hospital after the transplant. It is important that you understand this and discuss it with your family before you have your operation. You will be very vulnerable to infection at this time and you will be busy with your recovery and rehabilitation.**

## **Section 4:**

### **Life after Transplant**

#### **(A) RECOVERY AND DISCHARGE FROM HOSPITAL**

##### **The Cardiothoracic High Dependency Unit (CTHDU)**

###### ***Nursing Management***

When you are well enough to leave the ICU, you will be moved to the CTHDU. At this stage, most of the monitoring equipment will have been removed, but you may still have a monitor for your heart, a tube in your bladder, chest drains, intravenous medication and feeding tubes that were mentioned earlier. Over the following days, these will gradually be removed as your condition improves. You will be encouraged to eat, drink, move about, and take care of your own needs as you make progress.

Unlike the ICU, the nurse who is looking after you in the CTHDU will have other patients to care for also. You may feel a little unsettled to begin with, but remember that you would not have been moved unless your condition was progressing as expected.

###### ***Physiotherapy***

The physiotherapist will help you to become more active and you will become more independent as you recover. Please bring loose-fitting day clothes and suitable footwear with you – for example, track suit bottoms and T-shirts, and sandals with Velcro straps. You will need bigger sizes of clothes and shoes than usual. You will be expected to be out of bed most of the day.

The physiotherapist will help you plan your own exercise programme, which will help you reach your personal goals. This will include the use of an exercise bike once you are able for this. It is expected that you will continue this exercise on discharge from the unit. You will be shown how to fit a disposable mask to cover your mouth and nose when you are outside your room.

As you progress, you will be encouraged to become more active and mobile. You will be aiming to be able to walk the length of the corridor and climb a flight of steps before you are discharged. It is extremely important that you continue this

exercise programme once you are discharged home. You should get an exercise bike so that you can continue this exercise at home.

### ***Can my family bring in food for me?***

We advise family members not to bring in hot food or food that requires storage in a fridge. There are no facilities to keep food cold or to heat food on the ward. This is hospital policy. Re-heated food may cause stomach upset and interfere with your transplant medication.

### ***Can I have a family member with me to help with all this new information?***

We encourage your family to visit only at the set visiting times. This allows the transplant team to prepare you for discharge.

During visiting hours, you may have only two family members at a time.

All visitors must clean their hands using alcohol gel on entering and leaving the room but do not need to wear disposable aprons or masks. Relatives complaining of flu-like symptoms or upset tummy symptoms (vomiting or diarrhoea) must not attend the unit.

We do not allow patients who have already had a transplant to visit you in hospital. This is because of the risk of infection.

### ***Can my family or friends send me flowers?***

**No.** Plants or fresh flowers are not allowed.

### ***Planning for Discharge***

The CTHDU is where you will start to learn about your medications and the main complications you may experience after your transplant. As mentioned before, you will need to take immunosuppressive therapy and other drugs for the rest of your life. This helps to prevent the risk of organ rejection and reduces the risk of complications.

### ***The Lung Nurse Specialist***

During your recovery period, you will be visited by the Lung Clinical Nurse Specialist who will give you information about potential complications, follow-up care, transplant clinics and lifestyle changes after your transplant. It is important that a family member or carer is available for this discharge planning.



## **Getting ready to Go Home**

We make every effort to prepare you to be able to look after yourself and be independent by the time you are discharged. If your nursing team feel that you need more assistance, your individual needs will be discussed with the transplant team and your chosen carer on your behalf.

We encourage you and your carer to tell us about any problems with reading, writing or understanding information as soon as possible to avoid unnecessary stress. This will allow us to give you the information you need about new medication and lifestyle changes in a way that is suitable for you.

## **When will I be discharged home?**

Each patient will respond differently after the transplant, so this makes it difficult to predict how long you will be in hospital, especially if you were very unwell before the surgery. As soon as you feel well enough, and the team is happy with your progress, your discharge date can be planned.

The transplant team will give you, your relatives and carers information throughout your stay on life style changes post-transplant and follow-up care. The clinical nurse specialist will also talk to you before you are discharged about lifestyle changes, medication management, how to recognise the signs and symptoms of rejection and infection, what to do and who to contact, if these problems occur.

The dietician will meet you and your family during your stay in CTHDU to provide support and guidance and answer any questions you may have.

Please identify your main carer so that they can be present during these information and education sessions.

## ***Transport home***

It is your responsibility to organise your own transport to and from the hospital. Please do not use public transport for the first three months or for as long as the team advise. Public transport includes trains, buses and taxis.

## **Medications**

Before your discharge, you will be given a supply of medication to cover the first week at home. We will write to your GP informing them of your treatment so that you can get ongoing prescriptions. By the time you go home, you must be able to take your medications yourself and record them in the transplant diary.

## **Blood tests**

After your transplant, you will need regular blood tests to monitor for side-effects of the immunosuppressive therapy, and to make sure that your levels of immunosuppression are enough to prevent rejection. Your medication doses may change after these blood tests. Sometimes, your blood tests will happen when you have a clinic visit; other times, they can be organised locally with your local hospital or GP.

## **Equipment**

After you are discharged, you might need to use a 'BiPAP' or a nebuliser machine at home. These are ventilation support systems. You will be given instructions and advice about using any new equipment required before you go home.

If you have a medical card any new equipment will be provided through the local health board. However, if you are not a medical card holder, you will need to purchase any new equipment directly from the supplier. The Clinical Nurse Specialist will be able to assist with these purchase orders.

A letter will be sent by the Clinical Nurse Specialist to your oxygen provider telling them to remove any oxygen equipment no longer needed from your home.

## **Preparing your home for your discharge**

It is very important that your home is cleaned in preparation for your discharge

Ask someone to raise the head of your bed with 4-inch blocks under the legs at the head of the bed. Having the bed at an angle will reduce the risk of heartburn, heartburn can damage the lung.

## **Transplant Clinic**

The post-transplant clinic is on the seventh floor of the Whitty building. This is where you will have regular appointments with the doctors and nurse specialists after the transplant.

For contact details for the clinic and for contact numbers out of hours please refer to the front of this booklet.

We always aim to provide a quick and efficient service at the clinic. However, it is very busy and occasionally there are delays due to circumstances beyond our control. When you're due to visit the clinic, it is best to leave the whole day flexible, especially in the first few months after your transplant.

### **Schedule of clinic visits**

- Weekly for 4-6 weeks
- Fortnightly for 6-12 weeks
- Monthly for 3-6 months
- 2 Monthly for 6-12 months
- Then 3 Monthly

**Remember:** You will have follow-up transplant visits for the rest of your life.

Although you are encouraged to contact the transplant team at any time if you have problems or worries, it is always preferable to contact the clinic during office hours.

However, **do not delay in reporting symptoms** by contacting the clinic. If it is outside office hours, contact the Heart and Lung Transplant Ward.

### **Here are the contact numbers for both:**

Transplant Clinic: 01 803 4296

Heart and Lung Transplant Ward: 01 803 4322

***If you are unwell, always ring and speak to a doctor or nurse before coming to the clinic. By doing this, we can organise the tests you might need in advance.***

## (B) DRUG TREATMENT - A LIFETIME COMMITMENT



Before your transplant, you were most likely on regular medication. Now that you have had the transplant, your medication routine will be very different. It's vitally important that you follow the medication instructions you are given by the team.

### ***I've always taken medicines, what's different now?***

Post-transplant medicines can be very complex, with a lot of drugs to take. The new routine can seem difficult, but it is worth being very careful about taking the medicines correctly to give yourself and the new organ the best chance of success. Sticking with the drug treatment and follow-up programme is essential to ensure the best chance of a successful transplant.

After transplant you may still have to take all of the tablets, nebulised antibiotics and injections that you needed before the transplant as well as a number of new medications. You will need to take medicines at specific times. This is important so that we can get the dose right for you.

- You will need to take your medication every day and in the exact way the transplant team tell you.
- Never stop taking your medication even if you feel well.
- You are always at risk of rejecting your transplanted organs.
- Not taking your medication at the **right time** and in the **correct amount** is one of the common reasons for transplant failure.

Are there any general rules about how to take the medications?

There are some golden rules about medications after your transplant. Following these will help to give you the best chance of a successful transplant.

1. Never stop or start any medicine without checking with the transplant team. Your treatment is designed especially for you. If you have concerns or problems with your medicines, please talk to the team. Do not alter your treatment yourself. If you follow the rule of checking with us before taking new medicines, this will help protect you from 'interactions' – where one drug can stop another from doing its job.
2. Many commonly used medications interact with transplant medicines.

***You must never take these medicines:***

**Examples include antibiotics such as:**

- Clarithromycin (also known as Klacid®),
  - Fluconazole (also known as Diflucan®),
  - Anti-inflammatory medicines, for example Ibuprofen (Nurofen®) Mefenamic Acid (Ponstan®) Diclofenac (Difene®, Voltarol®).
3. **Remember do not stop or start a medicine without checking with the transplant team.**

We include over-the-counter, non-prescription and herbal or alternative medicines in this rule. If you are considering taking any preparation, tablet, cream, inhaler, vitamin, patch, then you must check with the transplant team first. Even a topical medicine e.g. cream or patch can be absorbed into your body and can affect your medication levels or your other treatment.

4. Do not take herbal medicines, alternative medicines, extra vitamin supplements, extra dietary supplements, homeopathic medicines, herbal teas or green tea. No matter where they were bought from (e.g. over the internet, from a health food shop or even a pharmacy), these may interact with your transplant medicines or cause kidney damage.
5. You may be more likely to get side effects from medicines. For example, it is more common to get severe ankle pain (tendonitis) from antibiotics from the quinolone family for example ciprofloxacin or levofloxacin. If you develop this pain stop taking the antibiotic and contact the transplant team.
6. We advise you to read the leaflet for all of your medications and speak to us if you have concerns. If you follow the rule of checking with us before taking new medicines then this will help protect you from interactions.
7. Please discuss with the transplant team if you are thinking about starting a family, as we may need to alter your medicines. This rule applies to both men and women.
8. Vomiting, diarrhoea or constipation may all affect the amount of medicine that you absorb. It is important that you do not become constipated and that you report vomiting or diarrhoea to the team.
9. Do not eat grapefruit or drink grapefruit juice. Also do not eat pomelo (a fruit like grapefruit), pomegranate or fresh ginger.
10. Record your medications every day in the drug diary. Bring this book to each transplant clinic appointment, and note any new instructions you're given at the clinic. This will help to make sure that you are taking the correct medications every day.
11. Keep your medicines in a safe place, and out of sight and reach of children.
12. We recommend that you keep your medications in their original containers. This will help you to become familiar with them. Some of the transplant medicines are sensitive to light and air and cannot be put into pill boxes or blister packs. Please talk to the transplant team before asking your community pharmacist to repackage your medicines for you.
13. On clinic days, do not take your medicines until after your blood test, but please bring your medicines to the clinic with you.

***What about taking food with my medicine?***

You can take a snack / meal with your 10:00 and 22:00 transplant medicines if you wish. You must be consistent about when you eat as this can change the levels of the transplant medicines in your body.

***How should I store my transplant medicines?***

We recommend storing them in a large roomy box. Keep it clean and tidy. Take out any medicines that you are not using and return them to your pharmacy. Keep your medicine in its original box – the transplant medicines are light and air sensitive and need careful storage.

***Have you any tips about taking the medicines?***

Taking your medicines needs full concentration.

- Find a quiet place where you can concentrate.
- Write out your medicines in the transplant diary.
- Take out the medicines you are going to use.
- Go through your diary one line at a time and count out the correct number of tablets into a bowl /cup.
- Take them!
- Tick off the medicines that you took on the list.

***I find taking medicines difficult, what can I do?***

It is important to have a routine for taking your medicines, and this routine must work seven days a week.

Please be honest with the transplant team if you are having any problems with taking your medicines in the way that we have asked you to. We have a lot of experience in helping people who are having problems with remembering to take medicines, difficulty reading or writing, poor sight, deafness and physical problems taking medicines.

It is better to be honest than to try to hide the problem. If you are not taking all of your medicines correctly it may reduce the success of your transplant.

### ***How do I make taking medicines a routine?***

Taking your medications exactly the way you are told to is vital. Therefore, it is important to get into a fixed pattern or habit of taking your medication every day. Here are some tips that might help you to get into a regular habit of taking your meds.

- Think about what pattern will fit best with your routine at home.
- Think about your work commitments, childcare, meal times, and so on, and maybe use these as prompts which will help you to “remember to remember” to take your medicines. It is important to get this pattern established in hospital.
- Think about weekends/holidays and other ‘special’ days. Your routine for taking medication must work seven days a week, so think about how you will manage at times when your routine may be different.
- Consider setting an alarm on your phone or some other reminder.

The transplant team will be paying careful attention to how you are getting on with learning to take your medicines.

To help you and your relative or carer in the process of taking your medication, we give you a book which is called the ‘transplant medication diary’.

#### **This is a diary where you should:**

- record all your drugs, the dosage you take and the times they’re to be taken at.
- record any concerns you have, or anything significant that you feel needs to be recorded.

#### ***You must bring this book with you to each transplant clinic appointment.***

Also, bring it to hospital if you are being admitted. It contains very important information about your treatment and helps to prevent errors which could harm you.

Remember, you are responsible for making sure you do not run out of your medications. You will be given a one-week supply of medications when you are being discharged, and you’ll be given prescriptions to get more from your usual pharmacy.

After that, the transplant team will continue to prescribe immunosuppressants and other medicines which are on the “high tech” scheme for you, but you will need to get prescriptions for the other medications from your GP.

You can contact the transplant unit for advice in an emergency.



## ***What medicines will I have to take?***

You will have to take medicines to keep you healthy and prevent rejection (immunosuppressants). You will be also be taking antibiotics to prevent infection and also medicines to prevent some complications of transplant.

- All medicines have side-effects. Some are minor, some can be more unpleasant. If you experience side-effects, talk to the transplant team.
- Drug therapies change as new research is carried out. The transplant team will keep you up to date with any new information about treatments.
- Information about medications changes from time to time, always request a patient information leaflet with you medications. If there is information in the leaflet that causes you concern or that seems to contradict information from the transplant team then please speak to a member of the transplant team. Never make any changes to your treatment without checking with the team.
- You will be taught about all the medications and the reason for taking them before discharge from hospital. You will take medications under supervision while you are still in hospital. You will then be able to continue the routine when you go home.

## ***Immunosuppressive medicines:***

After your transplant, you will need to take immunosuppressive drugs for the rest of your life. These drugs help to stop your body from rejecting your new organ, but they also increase the risk of infections and may cause other side-effects. There are a number of immunosuppressive drugs available. The team will chose the combination that will work best for you.

You will also be prescribed antibiotics some of which need to be taken lifelong. Most of the medication that you are taking before the transplant will need to be continued after the transplant. You will be given more specific information about the medication after transplant. (See appendix 1 for more information).

## **What about the other medicines I took before transplant?**

**You may need to restart other medications you were on before your transplant. For example, if you have Cystic fibrosis, you will need to restart Creon, vitamin supplements, and nebulised antibiotics. Patients with heart conditions may have to restart diuretics. If you were taking medicines to help your mood then it is important to continue taking them. Discuss any**

**regular medications with the transplant team prior to your transplant so that we are up to date with your treatment. This is especially important if you are started on new medication while you are waiting for transplant.**

***Will I be taking the same medicines forever? I met another transplant patient who was on different medicine to me. Why is that?***

Treatment and therapy change over time as we learn more from research and gain more experience. Having a transplant is unique to each patient. Your treatment and drug dosages may be quite different from another patient who has had the same operation as you.

**Remember always take the medicine that you have been prescribed and read any instructions carefully.**

**Never** take other medications before double-checking with the transplant team.

Always ask the transplant team for advice if you have questions about medication.

***What are the vaccination requirements for transplant patients?***

While you are waiting for transplant you should aim to have all the vaccines that are recommended for someone of your age.

We particularly recommend that all patients who are waiting for a transplant or who have had a transplant should have a flu vaccine every year and a pneumococcal vaccine every five years. We may also recommend additional vaccinations prior to transplant for example, hepatitis B vaccination.

Sometimes new vaccines become part of national programmes; please check with us about your suitability for these vaccines.

Not all vaccines can be given to transplant recipients, and you should take care to avoid the 'live' vaccines (where the vaccine is made from the whole virus itself – for example, the measles vaccine or some types of polio vaccine). Remember that as your immune system is suppressed, you may not get the full effect from a vaccine and you should not assume that the vaccine has been effective.

Please check with the transplant team if you have questions about travelling abroad and vaccines.

## (C) COMPLICATIONS AFTER TRANSPLANT

This section covers the most common transplant complications, and how these are diagnosed and treated.

**The most common complications are:**

- Rejection
- Infection
- Kidney problems
- Hypertension
- Diabetes
- High Cholesterol

Each one of these is discussed in more detail below.

### Rejection

#### *Rejection Following Lung Transplantation*

Your immune system is your body's main defence against disease and is made up of many different types of cells. Some of these cells are able to attack and destroy bacteria and viruses that invade your body; other cells help your body to become 'immune' (resistant to disease). Unfortunately, the body can't tell the difference between an infection and your newly transplanted organs. To try and stop the immune system from destroying the transplanted organs, you must take immunosuppressive medication.

Rejection episodes can occur any time after your transplant, and you should expect them. If rejection is detected early, then most rejection episodes can be treated effectively. Sticking to your medicine programme can help minimize the risk of rejection.

The medications mentioned below reduce the activity of your immune system after transplant and reduce the risk of rejection. You will be prescribed some of these however the choice of medication and the dose varies from person to person.

Ciclosporin (Neoral<sup>®</sup>)  
 Tacrolimus (Prograf<sup>®</sup>)  
 Azathioprine  
 Mycophenolate mofetil  
 Sirolimus (Rapamune<sup>®</sup>)  
 Prednisolone

## ***Acute Rejection following Lung Transplantation***

Acute rejection must be detected and treated early to help prevent irreversible damage. Always contact the transplant team if you ever think that you are experiencing signs of rejection. Acute rejection occurs most often in the first year.

If you have any of the following symptoms inform the transplant team as soon as possible.

### **Warning signs of possible Rejection**

- Shortness of breath
- Reduced ability to exercise
- Spirometry (lung capacity test) readings down by 10% or more three times in a row
- Unexplained tiredness, not being able to perform physical activity that you could do before
- Increased sputum (phlegm) production
- Mildly raised temperature (above 37.5°C or above 99.5°F)

### ***Diagnosis***

To detect rejection before the symptoms appear, you will have a series of routine examinations and investigations at set intervals after your transplant. Usually, you'll have these done as an outpatient.

### **These may include a combination of the following:**

- Physical examination and a review of your history
- Blood tests
- Lung biopsy
- Chest x-ray
- Lung function test

The most reliable way of diagnosing rejection is by taking a biopsy of the lung. In other words, a small piece of lung tissue is removed for examination. This is taken during a procedure called a 'bronchoscopy'. This is explained in more detail below.

Some types of rejection can be found by testing the blood for antibodies against the transplanted organ.

## ***Bronchoscopy***

A bronchoscopy is an examination of your windpipe (trachea) and your airways. It allows small samples to be taken for examination under the microscope (biopsy). It can also enable a 'lavage' to be performed – that is, washing out the windpipe and airways. A bronchoscopy is performed routinely after a transplant. It may also be performed if rejection or infection is suspected.

The bronchoscopy procedure lasts about 20 to 40 minutes. You will be sedated while it is happening. At the end of the examination, the tube is removed quickly and easily. After the bronchoscopy, you will be transferred to the recovery room. Your pulse, temperature, blood pressure and oxygen levels will be monitored for one or two hours. You may also need oxygen for a short time afterwards. You might experience a slight discomfort in your throat, but this will pass after a short while. Because of the sedation, you may not be allowed to eat or drink for two hours after the test. If you have had a biopsy taken, you may find streaks of blood in your sputum, but this should ease within 24 hours.

There are complications associated with this procedure, and these will be discussed with you when you are giving consent.

## ***Rejection Treatment***

Treatment for rejection will depend on the following:

- How severe the rejection is (what 'grade' of rejection)
- Previous rejection episodes
- Your current anti-rejection medicines

You may be given an injection of steroids once a day for three days. You may be admitted for this treatment. Alternatively, your dose of oral steroids may be increased. If your rejection is severe, or ongoing, you may need to receive an additional, or different, anti-rejection drug. The transplant team will discuss this with you.

## ***Chronic Rejection***

Chronic rejection in the lungs can appear as early as six months after the operation. This rejection is called 'obliterative bronchiolitis' (OB or BOS). In OB, the small airways of the lungs become blocked by scar tissue. The lungs will not function well, and you may become short of breath. Your lung function tests will

have deteriorated over time. The changes in the lung due to chronic rejection may start before you are aware of any symptoms.

### ***Treatment of Chronic Rejection***

Although this condition can be treated, it cannot be cured. Treatment of chronic lung rejection can be difficult. There are a number of treatments available that may be considered, such as:

- Changing to different immunosuppressive drugs or changing the dose may slow down the process.
- Total lymphoid irradiation (TLI). This is a form of radiotherapy.
- Re-transplantation – although this is rare. A second transplant carries a much higher risk than the first one, and will only be considered as a last resort. Each person will be considered on an individual basis after a complete re-assessment. You may then be placed back on the waiting list. Medical complications of the first transplant may rule out a second operation.

## **Infection**

The immunosuppressive drugs that help prevent rejection will also make you more likely to develop certain infections. The first three months after the transplant is when you will be most at risk because you are taking your immunosuppressive drugs in high doses.

However, it is important to know that there is a continuing risk of infection for all transplant patients. Recurrent infection can lead to permanent damage to your transplanted lungs. It is important to know, and report, the warning signs and start treatment early.

Following discharge home, we recommend that you use a face mask in certain situations when in public places for the first three months after your transplant. When you come for clinic visits the mask should be worn when you arrive in the hospital and can be removed when you leave.

### **Infections are usually caused by the following:**

- Bacteria
- Viruses
- Fungi
- Parasites

**Warning signs of infection may include:**

- A drop in lung function (spirometry)
- Raised temperature, 37.5°C /99.5° F or higher
- Change in sputum colour, quantity or consistency
- Flu like symptoms – chills, aches, tiredness, headaches, dizziness
- Cough or shortness of breath
- Nausea and vomiting
- Diarrhoea
- Pain or burning on passing urine, or feeling you must pass urine constantly
- Wounds or sores that will not heal and may be warm to the touch

It is important to take your temperature every day in the morning. Someone whose immune system is suppressed does not always get high fevers. Contact the transplant team any time your temperature reaches 37.5°C /99.5° F or above.

Bacterial infections can be treated with antibiotics. However, it is essential that a swab of the infected area, or sputum sample, is taken before antibiotics are given. This is to find out the exact type of infection so that the most appropriate antibiotics are given. This will be decided by your transplant team.

You are also at risk from food-borne infections (food poisoning) from contaminated food. Symptoms can appear between one hour to a week after you've picked up the infection, but you'll usually have symptoms within 24 to 72 hours (1 – 3 days). Please contact the transplant team for advice if this happens.

***Cytomegalovirus***

Cytomegalovirus (CMV) is a common viral infection affecting patients after a transplant. CMV usually causes only a mild illness in healthy adults, but can cause a serious illness in patients who are immunosuppressed.

Symptoms may vary from a mild fever and flu-like symptoms to severe life threatening infection. The most common organs to be affected are the lungs, but CMV can have an effect on the digestive tract, liver, heart, kidneys and eyes. If you develop CMV, you may need to be admitted to hospital for treatment.

Blood tests may be taken regularly for the first six months after your transplant to monitor your susceptibility to the infection. This allows treatment to be given early.

## ***Aspergillus***

Aspergillus is common fungal infection (caused by mould) that can affect patients after a transplant. Minor infections are treated with medication given through a nebuliser, or are treated with oral medications. To help minimize the risk of aspergillus infection, we advise patients to avoid areas of building work dusty/musty environments such as hay or silage on farms, and garden compost heaps.

## ***Pneumocystis Carnii Pneumonia (PCP)***

This is another common infection that affects the lungs. However, to try to prevent this particular type of infection, you may take a drug called co-trimoxazole (Septrin®) which is very effective in preventing this infection.

## **Other Problems**

### ***Kidney Problems***

The kidneys filter blood, remove waste products and regulate the fluid balance in your body. We monitor your kidney function by measuring levels of certain chemicals in your blood and urine. In some patients, the kidneys fail to work properly on their own.

If this happens to you, the work of the kidneys may have to be taken over by a temporary dialysis machine. For many patients, this is a short-term measure, while the kidneys recover. Sometimes, though, the kidneys do not recover and then dialysis will have to be a long-term treatment and a kidney transplant may be considered.

Kidney problems are often seen after a transplant, and may be due to one of the following:

- The kidneys are very sensitive to changes in your blood circulation.
- The kidneys are also sensitive to some of the drugs you are given, especially ciclosporin and tacrolimus.

We monitor how your kidneys are working during and after the operation by measuring the amount of urine you are passing and the chemicals in your blood.

We monitor the function of the kidneys very carefully to try to minimize the risk of permanent damage.



## **Lifestyle Advice**

It is important that you follow a healthy lifestyle after your lung transplant. Exercise regularly, watch what you eat and drink and **never smoke**.

### **Your medication may make you prone to:**

- high blood pressure
- weight gain or weight loss
- diabetes
- high cholesterol

These risk factors, together with poor diet and lack of exercise, may lead to future health problems such as coronary artery disease. All of these will be monitored regularly and treated if necessary.

### ***Hypertension***

Following a transplant, many patients develop high blood pressure. This is thought to be partly related to the immunosuppressive drugs. High blood pressure does not always cause symptoms, and most people are unaware that they have it. Unfortunately, if it is left untreated for a long time, it may lead to an increased risk of stroke, heart or kidney problems.

Your blood pressure will be monitored regularly. For many patients, it will be necessary to start regular treatment to lower their blood pressure. You may be discharged on blood pressure medications. You can help to keep your blood pressure under control by eating a low salt diet and by losing extra weight.

### ***Weight***

You should weigh yourself on a standard bathroom scale at the same time each morning after going to the toilet. Record your weight in your transplant medications diary. If you gain more than 1 kg a day, please report this to the transplant clinic.

### ***Diabetes***

Diabetes can occur after a transplant. This is sometimes temporary, and is a result of stress and the medications you are given, such as steroid therapy.

If you need insulin, the diabetes team will begin teaching you about monitoring your blood sugar levels and how to give yourself your insulin.

If necessary you will be seen by the Diabetes Nurse Specialist whilst you are an inpatient, and then you'll attend the diabetes clinic as an outpatient. The team will monitor your blood glucose very carefully and will advise you about your diet, your tablets, or insulin if you need it. The dietitian will advise about your diet, to help you control your blood sugars.

Some patients may develop permanent diabetes after their transplant. If this happens to you, you will be referred to an appropriate specialist.

If you are already diabetic, having a transplant can upset your glucose levels, and you may need to have your medication or insulin adjusted to suit. If you had Cystic Fibrosis-related diabetes before your transplant, the new medications may make blood sugars more difficult to manage. You may have to change your diet and take a different dosage of insulin or even a different type of insulin.

The transplant dietician and the diabetic team will advise you about this.

### ***Cholesterol***

After a transplant, many people tend to have high blood cholesterol levels, partially due to their medications. Research shows that over 4 in 10 people who have had transplants have high cholesterol and triglyceride levels which may cause heart disease.

You should eat a balanced diet containing vegetables, fruit and wholegrain foods and avoid foods high in saturated fat.

See [www.indi.ie/diseases,-allergies-and-medical-conditions/heart-health/530-how-to-manage-cholesterol.html](http://www.indi.ie/diseases,-allergies-and-medical-conditions/heart-health/530-how-to-manage-cholesterol.html) Keep track of your weight – taking steps to avoid weight gain can help to control blood cholesterol levels.

After your transplant, your blood cholesterol level will be measured frequently. The ideal goal is less than 5mmol/l.

## **Less Common Complications**

This section looks at some of the rarer complications associated with transplants. Although they only affect a minority of patients, they can cause problems.

## **Gout**

Some of the immunosuppressive medications can cause gout – a build-up of uric acid in a joint causing it to swell. This can be quite painful, but it can be treated with medications. There are certain medications that you may be unable to take for gout because of your immunosuppressive therapy. Please contact the transplant team before taking any treatment.

## **Osteoporosis**

Osteoporosis is a thinning of the bones that is associated with long-term steroid use, poor diet, post-menopause or poor mobility. You will receive advice about prevention for this in the form of diet and exercise information. You will also be on medication to prevent or treat it.

For diet advice see: [www.indi.ie](http://www.indi.ie)

## **Cancer**

Unfortunately, people whose immune systems are suppressed are more prone to certain types of cancer. Immunosuppressant medications and antifungal medications reduce the body's ability to fight off early cancer cells.

The types of cancer seen are:

- Skin cancer
- Bowel cancer
- Cancer of the cervix
- Prostate cancer
- A type of lymphoma – a cancer of the blood cells (called Post-transplant lymphoproliferative disorder or PTLTD for short).

We will monitor you closely as part of your follow-up care, and we also recommend that you take part in the national cancer screening programmes (for example, BreastCheck, Cervical Check and the National Bowel Screening Programme) and attend any screening appointments made for you.

### **• Skin Cancer**

The anti-rejection medications you will need to take after transplant lead to a much higher risk of skin cancer.

Skin cancers are directly related to sun-exposure.

You don't have to avoid the sun completely, but it is very important for you to establish good sun safety habits as early as possible. It is possible to decrease your risk of getting a skin cancer by doing the following:

- "Slop on sun cream" first thing every morning - wear SPF 50 with UVA and UVB protection, all year around, on any exposed skin, for example, backs of hands, neck, face and lips. It is important to sun protect every day when outdoors here in Ireland, even on a cloudy day, or through a window and doubly so when overseas in the sun. Reapply every two hours.
- "Slip on some clothes" covering up with sleeves and trousers provides good protection from the sun.
- "Slap on a hat and shades" wear a wide-brim hat and wraparound UV-filtering sunglasses when outside.
- "Seek shade" when possible, but especially between 10am – 4pm.

It is also very important to check your skin regularly, and if anything is changing or growing, you need to be seen by a dermatologist as soon as possible – your transplant team will be able to arrange this.

### **What do I look out for?**

Self-examination – Once monthly, have a look at your entire skin surface, using two mirrors. Get a family member to help out with this if possible.

Rough red spots that come and go are due to sun-damage, and these are sometimes pre-cursors to skin cancers. These can easily be treated with a special cream or cold spray (cryotherapy) by a dermatologist.

A skin cancer may appear as a red, scaly bump on the skin, or an open sore that will not heal. A lot of the time, these are easily treated and cured, sometimes with a cream, or sometimes by surgically cutting them out under local anaesthetic. Remember, the earlier that these are found; the easier they will be to treat.

If anything is changing or growing, you need to be seen by a dermatologist, and your transplant team will be able to arrange this.

You should have an annual skin check starting shortly after your transplant. If you feel something is changing in the meantime – let your doctor know as soon as possible.

- ***Bowel Cancer***

Colorectal screening (examination of the large intestine and rectum) is recommended for both men and women aged 50 and older to detect signs of colorectal cancer.

The most common tests or procedures used to screen for colorectal cancer include:

- Faecal occult blood test (FOBT). This test is performed on samples of your stool to check for blood that may not be easy to see in the stool. This testing should be done every year in men and women aged 50 and older.
- Colonoscopy. This procedure is done by a gastroenterologist (GI doctor). The doctor uses a flexible, lighted tube called a colonoscope to look at the inside walls of the rectum and the colon (large intestine).

In addition to routine screening, it is very important to tell your GP or clinical nurse specialist about any changes in your stools or bowel pattern – for example, an increased or decreased amount of stool, a change in colour, a change in the firmness or texture of your stool (hard stools or liquid, watery stools), or the appearance of blood.

- ***Cervical Cancer and Breast Cancer***

We advise female transplant patients who are aged 18 or older and sexually active to have a gynaecologic examination every year.

Female patients are advised to follow the usual screening procedures for the early detection of cervical and breast cancer by going to their family doctor. This includes having a breast examination every year to check for changes in the breast tissue, and having cervical screening every year to detect any abnormalities of the cervix.

Women aged 40 and older should have a mammogram every year, and do a breast self-exam every month.

Women who have a family history of breast cancer or other risk factors may be advised to have a mammogram before the age of 40, or to have mammograms more frequently.

- **Prostate Cancer**

The prostate is a walnut-sized gland that is part of the male reproductive system. It is located in front of the rectum and below the bladder.

Prostate cancer is one of the most common forms of cancer in men. Male patients are advised to follow the usual screening procedures for prostate cancer by going to their family doctor.

A blood test called the 'prostate-specific antigen' test (PSA) is used to screen for prostate cancer. This test measures the level of a substance (antigen) produced by the prostate, and checks whether or not this level is within the normal range. We recommend that male patients have a PSA every year.

- **Post-transplant Lymphoproliferative Disorder - PTLD**

This is one type of lymphoma or cancer of the blood cells. A very small percentage of transplant patients may develop this condition which causes the lymph glands to become enlarged. A virus called Epstein-Barr, similar to glandular fever, can cause this. This condition is sometimes treated by reducing immunosuppressive therapy and having regular biopsies. PTLD can be treated with anti-cancer drugs (chemotherapy) and sometimes radiotherapy or surgery.

## **Neurological Problems**

(Problems of the brain and nerves)

### **Stroke (Cerebrovascular Accident)**

A stroke is a rare but serious complication of transplantation. If your circulation is being artificially supported during the transplant operation, it is possible that there be may a reduced oxygen supply to the brain. This may cause some of the brain cells to die.

In some cases, the effect of this damage is temporary, but in others, it may be more permanent.

Symptoms of a stroke include weakness down one side of the body, loss of sensation, and difficulty with speech or vision. The FAST campaign gives an easy way to recognise stroke symptoms – Face drooping, Arm Weakness or Speech problems. **If someone has these, then it is time to call 999 or 112.**

### ***Fits (Convulsions)***

Certain drugs and chemical changes in the body can cause fits. High levels of ciclosporin or tacrolimus have been known to cause fits shortly after surgery when patients are in the early stages of recovery. By adjusting the level of drugs and correcting the chemical imbalance, the fits should stop. Sometimes your immune medications may need to be changed to prevent further fits.

If you have had any sort of fit and you are a driver, you must report it to the National Driver License Service (part of the Road Safety Authority). You may be unable to drive for up to one year following your last fit. Rarely, infections of the brain can cause problems including fits.

### ***Digestive disorders***

Constipation can be a side-effect of some of the drugs you take. It is important that you drink plenty of water, eat foods that are high in fibre, and take laxatives if the transplant team advises them. Remember your medication will not be absorbed into your body properly if you have constipation and this could put you at risk of rejection.

<https://www.indi.ie/diseases,-allergies-and-medical-conditions/digestive-health/1248-fabulous-fibre.html>

For more dietary advice please see ***“Eating for Health”*** on page 61.

You may develop gallstones after your transplant due to the way the drugs work in your system. Gallstones may be treated with medications. However, some people may need surgery.

Less commonly, you may develop an ulcer in your stomach. This may be caused by drug therapy, stress or infection. Many people are on preventative therapy to reduce the risk of this occurring. Rarely, patients may experience serious problems such as bleeding or obstruction of the bowel.

## (E) COMING TO TRANSPLANT CLINIC



We are located on **7th Floor of the Whitty Building**. Look for the signs for **Heart Lung OPD/Bronchoscopy**.

During the clinic visit, you will be asked to take part in various tests and procedures such as a pulmonary function tests, chest X-Ray and blood tests. You will also be given a date and time for both clinic and blood test appointment.

We encourage each patient to schedule their own blood test appointment either on line: [www.mater.ie](http://www.mater.ie) or by calling 01 2910181.

**Every time you come to the transplant clinic, you need to bring:**

1. Your transplant diary – make sure it's filled in with a complete list of all your medications.
2. Your medications – you will need to take some of them after your blood test, but it is a good idea to bring all of them in case we need to check them.



3. A family member or carer.
4. A list of questions.
5. If scheduled for bronchoscopy or if you feel unwell please bring a small overnight bag with night clothes & toiletries.
6. This booklet!

**During your visit to the clinic, you need to report any health changes, such as:**

- Fevers
- Cough, sputum (colour, amount)
- Shortness of breath
- Weight gain or loss
- Constipation or diarrhoea, vomiting, heart burn
- Headaches
- Difficulty sleeping, changes in mood

***It is a good idea to record these symptoms as they happen in your transplant diary to help you remember.***

You will return to the transplant clinic once a week for the first 4-6 weeks after your transplant surgery. These visits may be reduced to fortnightly visits if your transplant team consider your recovery is proceeding without any complications. After three months, your visits will be scheduled for once a month for the next 3-6 months; then every second month, depending on how you are doing. You will then be followed up in the transplant clinic every 3 months lifelong.

We do everything that we can to stay on time, but delays of several hours are not uncommon.

**Remember:**

- Never run out of your transplant medication.
- Do not take your immunosuppressive medications until after your blood test.
- Bring your medications to clinic with you to take afterwards.

**Prescriptions repeats**

When you are discharged from hospital for the first time after transplant you will be supplied with enough medications for one week and you will be given a prescription for your pharmacy. The transplant doctors or nurses will continue to write prescriptions for medications that are on the “high tech” scheme. They will adjust the dosages of these medications according to your needs. Your regular repeat prescriptions should be written by your local GP.

Other medications – for example, antibiotics – may be prescribed on an emergency basis, or as needed for conditions that could affect your transplant, or to treat side-effects of your immunosuppressive medications.

Please do not take any medications that have not been prescribed or approved by the transplant team.

**(F) ADJUSTING TO LIFE AFTER TRANSPLANT**

Patients and their families often describe having a transplant as ‘an emotional rollercoaster’ with a huge range of feelings, responses and emotions from everyone involved.

Most of these emotions are normal and can range from relief, euphoria, and anxiety about going home or making lifestyle changes to frustration and guilt. The transplant team will provide advice and support around many of these changes. If you or your carers have questions, please ask. Remember, these emotions are normal, and we are happy to help you deal with them.

Many post-transplant patients feel they should feel happy all the time, and that they are the only person experiencing negative emotions. It is important to remember that how you feel post-transplant is unique to you and your life story. It is different for everyone.

Many patients have a huge sense of expectation that they should be more active or feel better than they do. Please remember that recovering after a transplant and feeling ‘normal’ again takes time and patience. The transplant team will advise you about how much activity/exercise you should be doing.

If you, your family or carers notice any significant or prolonged changes in your mood, you should speak with a member of the transplant team. It is important to do this, as we can check if there is any medical reason for these changes or low mood. Psychological support or counselling is available via the Medical Social Worker or Psychologist on the team – please speak with any of team about referral.

It is also important to remember that you can develop strategies or ways of coping that will help you to deal with your emotions. Some things that may help include:

- Exercise\*
- Learning ways to relax (yoga, Tai Chi, mindfulness including mindfulness apps, music, and so on)\*
- Recognizing how you feel and asking for help if you need it – talking to friends or family can help
- Establishing a good routine
- Eating a healthy diet\*
- Participating in social activities\*
- Developing interests and hobbies\*
- Joining support groups or talking to other transplant patients – a list of support groups is in the front section of this booklet
- Talking to the Medical Social Worker or psychologist may be useful for some people – speak with the transplant team about this.

*\*Always check with the post-transplant team before starting any activities or exercise.*



*Jill McElhinney at the summit of Croagh Patrick. Jill underwent a lung transplant and was able to complete this challenge after training.*

Photo by kind permission of Jill

## General advice

### “Dos and Don’ts”

#### DO:

- Follow the diet advised by transplant dietician.
- Continue your walking exercise. To begin with, this may be around the garden. Build up gradually and keep the distance very comfortable.
- Continue your physiotherapy and exercises every day.
- Eat well to promote wound healing.
- **Only use medicines which have been prescribed and recommended by the transplant team.** (This is because some over-the-counter medications and herbal preparations available from a pharmacy can interact with your transplant drugs this could cause rejection or damage to your kidneys.)



#### In the initial three months after transplant **DO NOT:**

- Lift, push or pull anything heavy – that is, over 1kg which is equal to a bag of sugar. Therefore, don’t, for example, lift children, move furniture, clean your car, do heavy housework such as vacuuming or heavy gardening such as mowing or digging.
- Play any contact sports or take part in any other activities that may put pressure on your wound.
- **Drive until you are told you may do so by your transplant doctor.**
- Carry out any DIY that involves heavy stretching or lifting.
- Overdo your exercises. Listen to what your body tells you.
- Take medicines which have not been prescribed by the transplant team.



# Eating For Health

## Eating for healing

### Why is it important to eat well after the transplant?

Eating well is a vital part of your recovery and rehabilitation. Eating well helps your wound to heal, improves your muscle strength and generally speeds recovery. Protein is a very important part of your diet during your recovery. Good sources of protein include: Fish, poultry, lean meat, eggs, legumes or lentils (kidney beans, chickpeas, beans, red lentils, etc), dairy products (milk and yoghurt), soy products (tofu, soy milk, soybeans), nuts, seeds and nut butter. You should have at least one of these protein foods in each meal. The dietician will meet you and your family to provide support and guidance and answer any questions you may have. Remember: Everyone is different! Your nutrition needs may change if you have complications or side effects from your medications after transplant.

### Eating for health - if you have been told to gain weight

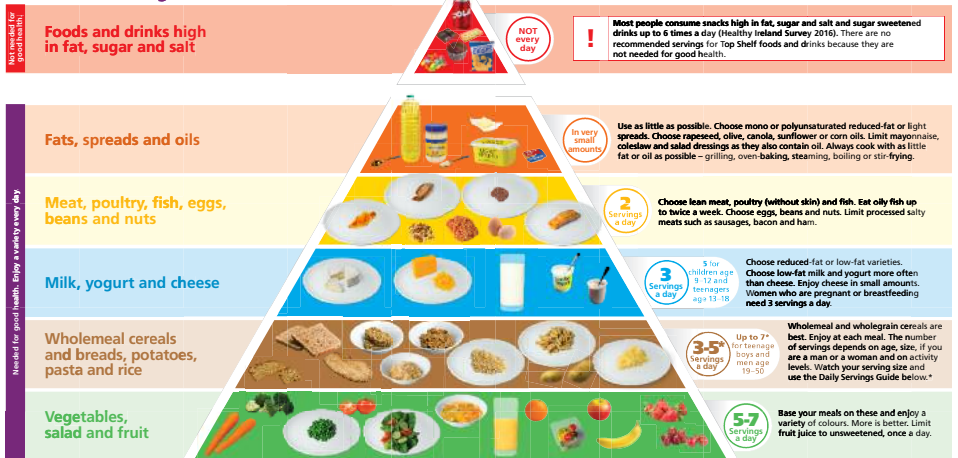
#### Healthy Food for Life

www.healthyireland.ie



#### The Food Pyramid

For adults, teenagers and children aged five and over



#### \*Daily Servings Guide – wholemeal cereals and breads, potatoes, pasta and rice

Active	Child (5-12)	Teenage (13-18)	Adult (19-50)	Adult (51+)	Inactive	Teenage (13-18)	Adult (19-50)	Adult (51+)
Active	3-4	4	4-5	3-4	Inactive	3	3-4	3
Inactive	3-5	5-7	5-7	4-5	Inactive	4-5	4-6	4

There is no guideline for inactive children as it is essential that all children are active.

#### Average daily calorie needs for all foods and drinks for adults

Active 2000kcal Inactive 1800kcal Active 2500kcal Inactive 2000kcal

#### Serving size guide

**Cereals, cooked rice and pasta, and vegetables, salad and fruit**  
Use a 200ml disposable plastic cup to guide serving size.

**Cheese**  
Use two thumbs, width and depth to guide serving size.

**Meat, poultry, fish**  
The palm of the hand, width and depth without fingers and thumbs, shows how much you need in a day.

**Reduced-fat spread**  
Portion packs found in cafes can guide the amount you use. One pack should be enough for two slices of bread.

**Oils**  
Use one teaspoon of oil per person when cooking or in salads.

**Drink at least 8 cups of fluid a day – water is best**

**Get Active!**  
to maintain a healthy weight adults need at least 30 minutes a day of moderate activity on 5 days a week (or 150 minutes a week); children need to be active at a moderate to vigorous level for at least 60 minutes every day

Source: Department of Health, December 2016.

It is important to eat a balanced diet containing enough energy and protein

If you are underweight or your appetite was poor before your transplant, it is important to follow the advice below to improve your recovery.

To increase your nutritional intake, you should try to:

- eat little and often – include nourishing drinks, meals and snacks for example, use full-fat milk, eat scones, milk puddings, and full fat yoghurt. Include a high protein food as listed above at each meal.
- choose full-fat products, and avoid anything labelled as ‘reduced’ or ‘low- fat’.

If you continue to lose weight speak with the transplant team.

### ***Eating for health - if you have been told to lose weight***

After your transplant, you may experience a few things that can cause you to gain weight:

- You have an increased appetite due to steroids.
- You may enjoy food more when you are feeling better and start eating more
- Your body may not be working as hard (using as much energy) once your new organ is functioning well.

Being overweight increases your risk of high blood pressure, coronary artery disease, raised cholesterol and diabetes. It may also limit your mobility.

Aim to achieve a healthy weight for your height by keeping your Body Mass Index (BMI) within the healthy range and avoid gaining excess weight. See [www.INDI.ie](http://www.INDI.ie) for more information.

### **To help prevent too much weight gain, here are some tips to follow:**

- Eat a well-balanced diet as per the **Food Pyramid**.
- Meals should be eaten regularly. Avoid long periods of fasting. Aim for three meals a day.
- Limit foods that are high in fat, sugar and calories. Example of these are chocolate, sweets, cakes, pastries, ice cream, crisps, fried foods, sugary drinks, high calorie fast food and take-aways.

- Include carbohydrate foods at each meal. This includes bread, potatoes, rice or pasta. Ensure your portions of these foods are not too large. Follow the Food Pyramid guide for portion advice [www.safefood.eu/Healthy-Eating/What-is-a-balanced-diet/The-Food-Pyramid.aspx](http://www.safefood.eu/Healthy-Eating/What-is-a-balanced-diet/The-Food-Pyramid.aspx)
- Have at least five portions of fruit and vegetables each day.
- Include more high-fibre foods such as: legumes and lentils, whole grains (brown bread/pasta/rice or high fibre cereals) and fruit and vegetables.
- Avoid adding salt to your food (this is not applicable to people with Cystic Fibrosis). Try using other flavourings instead – for example herbs, spices, pepper and garlic.

## Food Hygiene

After your lung transplant, you will be taking immunosuppression drugs to prevent rejection. This medication can lower your body's natural resistance to infection.

The following information is to help reduce the risk of you developing food poisoning (gastroenteritis).

### General Information

Follow a hygienic way of living, and pay attention to your personal hygiene. Get into the habit of washing your hands regularly, especially after using the toilet, or having contact with animals. Always wash your hands before and after handling food. Make sure all kitchen surfaces, hobs and utensils are clean before you use them.

Clean as you work. Mop up any spills immediately, and change dishcloths and tea towels every day. Clean out kitchen cupboards regularly, as crumbs can attract pests.

Use separate chopping boards for raw meats and vegetables or breads. Throw out chopping boards when they become scored with knife marks. Do not eat foods that are past their best before date (unless you have frozen it in line with the instructions on the box. Throw out tinned foods if the tins have bulges. Store raw meat by itself on the bottom shelf of fridge. Never allow other foods to come into direct contact with raw meat. Keep cooked and raw meats separate – both when you're storing them at home and when you're shopping.

### ***Chilled Foods***

Fridge temperature should be between 0°C and 5°C. Keep your fridge clean – wash it out with warm water and bread soda once a month or when spillages occur. Do not overfill the fridge as it raises the temperature. Throw out any out-of-date food.

### ***Frozen Foods***

Buy frozen foods last when you're shopping. Never thaw and refreeze foods. Defrost food in the fridge rather than leaving it on the countertop. Always follow the instructions on the packaging for cooking methods.

### ***Cooking & Reheating Foods***

Always follow cooking instructions carefully on ready to eat, convenience or prepacked foods. Ensure that meat and poultry are well cooked until the juices run clear and not pink in the middle. If reheating food, use a microwave and ensure food is piping hot in the centre and throughout before serving. Leave food to stand after cooking or after reheating in a microwave as the food continues cooking for about a minute after microwave is turned off. Never reheat food twice.

### ***Drinking Water***

Drinking water is frequently contaminated with bacteria at different times of the year in many parts of the world including Ireland and so precautions should be observed wherever you live in the country at all times.

- All tap water must be boiled before drinking.
- Bottled water, including sparkling, can be drunk directly.
- Wash storage container daily with boiled hot water and washing up liquid. Store water in fridge between 0°C & 5°C.
- Refill container daily – do not top up container.
- Use boiled water to make ice cubes.
- NEVER drink water directly from lakes or rivers.
- NEVER use ice cubes in restaurants / bars

### ***Eating Out***

In general eating out should be avoided for the first three months after your transplant. However discuss it with your transplant team as this may vary from person to person. If you eat out, choose a place with a good standard of hygiene and catering. Choose hot dishes where possible as they have a lower risk of contamination.



## High Risk Foods

Higher risk foods to avoid	Lower risk alternative
<p><b>Meats and seafood</b></p> <ul style="list-style-type: none"> <li>• Raw or undercooked meat, poultry, fish</li> <li>• Sushi, smoked salmon, pate</li> <li>• Shellfish – prawns, oysters, mussels, crab</li> <li>• Delicatessen food such as prawn cocktail</li> </ul>	<ul style="list-style-type: none"> <li>• Thoroughly cooked meat, poultry, fish</li> <li>• Canned fish</li> <li>• Frozen meat, poultry, fish – ensure cooked thoroughly</li> </ul>
<p><b>Milk and dairy products</b></p> <ul style="list-style-type: none"> <li>• Unpasteurised dairy products</li> <li>• Soft cheeses such as stilton, camembert, blue cheese</li> <li>• Soft serve ice cream – (“99” type icecream)</li> </ul>	<ul style="list-style-type: none"> <li>• Pasteurized dairy products</li> <li>• Desserts made from pasteurised milk or cream</li> <li>• Philadelphia cheese and hard cheese such as cheddar or parmesan</li> <li>• Dairy products containing live bacteria, e.g. Actimel, Everybody, Danone yoghurts are suitable as long as the milk is pasteurised</li> <li>• Always check labels</li> </ul>
<p><b>Egg and egg products</b></p> <ul style="list-style-type: none"> <li>• Raw egg or part boiled egg</li> <li>• Custard or ice cream made from raw egg</li> <li>• Mayonnaise made from raw egg</li> <li>• Dishes containing part cooked eggs, e.g. carbonara</li> <li>• Cold desserts made with raw fresh egg.</li> </ul>	<ul style="list-style-type: none"> <li>• Hard boiled or well-cooked fried egg</li> <li>• Scrambled egg, cooked all the way through</li> <li>• Dishes and desserts made with egg that are cooked thoroughly</li> <li>• Dishes made from pasteurised liquid egg</li> <li>• Commercial mayonnaise made with pasteurised egg</li> </ul>
<p><b>Fruit, vegetables and grains</b></p> <ul style="list-style-type: none"> <li>• Re-heated, cold rice</li> <li>• Unwashed, mouldy, damaged fruits</li> <li>• Raw mushrooms, lettuce, cabbage</li> <li>• Salads on mass production (e.g. deli coleslaw)</li> <li>• Raw berries</li> </ul>	<ul style="list-style-type: none"> <li>• Hot, freshly cooked rice</li> <li>• Fresh fruits (undamaged) that have been washed in bottled water or peeled</li> <li>• Cooked fruits</li> <li>• Cooked vegetables</li> <li>• Thoroughly washed (in bottled water) tomatoes and peppers, washed and peeled cucumbers and carrots</li> </ul>

- Other fruits to avoid include grapefruit and pomegranates due to their interactions with some of the transplant medications.

## Exercise and activity after transplant

You will have been given advice from the physiotherapist about suitable exercise and exercise targets to help you get the best benefit of your transplant. It is important that you make time in your day for this.

It can be hard to develop a new routine of exercise after transplant, and it may seem like there is often a reason to skip exercise – if the weather is bad, or you think you don't have the right clothes, and so on.

It can take more than six weeks to make exercise a habit, so don't get discouraged. Here are some tips that might help to motivate you.

- Vary your activities – for example, walk sometimes; cycle sometimes.
- Remember that you don't need special equipment or the latest fashionable gym gear. Just be comfortable.
- Make a commitment to another person to go walking or cycling with them.
- Make exercise a priority, and let others know that it is now part of your life.
- Set times for your exercise.
- Log your activity in your transplant diary.
- Notice your progress!
- Reward yourself for your efforts.



*David Crosby completes the New York marathon. David underwent a lung transplant and was able to complete the marathon following training.*

Photo by kind permission of David

## Keeping Pets

Household pets are a potential source of bacteria and infection. Here are some tips that might help you to stay well if you share your home with a pet.

- Get advice about keeping pets from your doctor and vet.
- Make sure that pets are kept healthy – for example; make sure they are wormed and vaccinated regularly. Some pet vaccinations are “live” vaccinations and can pose a risk to transplant recipients.

- Practise good standards of hygiene.
- Keep pets out of the kitchen and never allow them near foods or on worktops.
- Prepare your pet's food on a separate surface, and use utensils specially kept for that purpose. Never use the same utensils or the same work surface for preparing food for human consumption.
- Don't let pets lick your face, or sleep on your bed.
- Be careful when changing cat litter trays. Wear thick rubber gloves and wash your hands afterwards. Cats can carry toxoplasmosis, an infection that can affect immunosuppressed patients.
- Don't keep birds or reptiles as pets.

## **Smoking and Alcohol**

### ***Smoking***

You must never smoke after your transplant. If you are ever tempted to smoke, please ask for help. Passive smoking can also have a detrimental effect on your health – especially if you live with a smoker.

### ***Tattoos and Piercings***

The risk of infection from a tattoo or piercing is increased after a transplant. We recommend you avoid these.

### ***Contact Sports***

Contact sports such as football, boxing, or martial arts should be avoided after your transplant as you could get a bang on your chest.

### ***Hair Care***

Transplant medicines can change the condition of your hair. Tacrolimus (Prograf) can cause hair loss or thinning. This usually stops or slows down as you have your dose lowered over time. We advise that you wait at least three months before you have your hair coloured as dyes may cause your hair to become more brittle and break. Avoid permanent hair colour e.g. peroxide based.

Some medications can cause unwanted body hair growth. Please speak to the transplant team before you have any treatment such as waxing or electrolysis. This is because your skin will be easily damaged after transplant by these treatments.

## **Alcohol**

You should not drink alcohol after the transplant until the transplant doctors decide you are fit enough to do so.

Some patients will be advised to avoid alcohol for life.

If you are given permission to drink alcohol, you should drink no more than one or two units a week.

### **One unit of alcohol is equivalent to:**

- half a pint of beer.
- a single measure of spirits.
- 125ml glass of wine.
- a small glass of sherry.

Exceeding these levels can be harmful; as it can interfere with the way your immunosuppressive drugs work. The combination of alcohol and the medications can damage your liver.



*Joan Lynch and family before the Mini Marathon. Joan had a lung transplant and trained for this event. Photo by kind permission of Joan*

## ***Sexual Activity***

You can resume sexual activity as soon as you feel ready and your wounds have fully healed. (Further advice can be given on an individual basis).

Patients who have had problems with sexual function before their transplant will not necessarily notice any improvement after the transplant. Please ask the transplant team for advice if you think it might be helpful.

If you need birth control advice, you need to see one of the transplant doctors, as certain contraceptives are more suitable than others. It is important to ask advice before planning to have children as your medications may need to be adjusted. This applies to both men and women.

## ***Pregnancy***

Pregnancy can have a serious impact on your health after a transplant. It is essential that you discuss your intention to become pregnant with the transplant team before you conceive, especially if you have been prone to rejection or infection.

It is unwise to think about a pregnancy until your medical condition has stabilized, and especially during the first year after transplantation. If you are thinking about becoming pregnant, you must discuss this with one of the transplant team, so that you can be fully informed about the risks involved.

For example, some of the drugs you'll be taking after your transplant could cause abnormalities in the unborn child.

Due to radium exposure from x-rays, you must tell the medical staff as soon as possible if you think, or have any suspicion, that you may be pregnant.

If you suspect you may be pregnant, please discuss this with the transplant team as soon as possible. We will be happy to support and advise you.

## ***Infertility***

Some of the medications, such as valganciclovir, can affect your fertility. Please talk to the medical staff for further information. Male patients may wish to bank sperm before they start taking medications. You can talk to the transplant team about this before the drug therapy starts. However there may not be time for this to be arranged if medication needs to be started quickly because of your condition.

## **Holidays**

We recommend that you do not travel abroad in the first year after your transplant. If you are planning a holiday, please talk to us about your choice of location in advance. Some countries where standards of food and hygiene are poor, or where adequate medical treatment is hard to come by, may be particularly dangerous.

Before a journey, you may be asked to produce a medical letter for insurance purposes, stating that you are fit to travel. Please give as much notice as possible for these requests (at least three weeks). You might have to come to the clinic for a check-up before this is issued.

**It is essential that you carry your immunosuppressive drugs in your hand luggage.**

**Bring more medication than you think you will need for your trip.**

Please ensure that you are adequately insured. When buying holiday insurance, please make sure that the company is aware that you have had a transplant – otherwise your policy will be invalid.

We advise you always to insure your holiday against last minute cancellations due to medical problems, and to make sure that you can fly home immediately if you become unwell while you are out of the country. Remember that excessive sunlight can cause premature ageing and skin cancer.

## **Care of teeth and gums**

***Do not have dental treatment for the first three months after a transplant.***

After three months, if you need treatment, the dentist may decide to give you an antibiotic to prevent infection while you have dental treatment. The transplant team can advise on suitable antibiotics if required.

Some post-transplant medications can cause overgrowth of the gums that, in turn, can cause discomfort and problems with eating. This can be controlled to some extent by maintaining a high standard of oral hygiene. Sometimes, though, the gums need to be treated by a dental surgeon.

Using an electric toothbrush is recommended as well as regular scaling and polishing.

Oral thrush can also cause a sore mouth, and if left untreated, it may result in a white, furry coating on the tongue and inside the cheeks. At this stage, it can be very difficult and painful to eat. This can be treated with an antifungal drug.

Teeth and mouth infections can be particularly serious, so make sure you have your teeth professionally cleaned twice a year. Check with the transplant clinic in case you need to take antibiotics before the cleaning.

### **Optician**

We recommend that you have an eye test every year to check for glaucoma and cataracts. Patients receiving long-term frequent steroid therapy should have a yearly eye test too.

Your eyesight may be affected temporarily after the transplant. Therefore, you shouldn't have an eye test for the first few months, unless you are experiencing major visual problems.

## **Returning to Work**

We would hope that most patients should be able to think about returning to work six months after their transplant, however this varies from person-to-person. Please discuss this with the transplant team.

## **Other points to remember**

- If possible, stay away from people who are obviously sick with colds or other signs of infection.
- Be particular with personal hygiene, and check your skin for cuts, boils, bruises and so on. Report these to the transplant team.
- Good oral hygiene is important – (see 'Care of Teeth and Gums'). Brush your teeth at least twice a day, and check for bleeding or ulcers. Visit your dentist at least twice a year.
- Avoid crowded areas for at least three months after your transplant – for

example buses, trams, trains, airports, theatres, pubs restaurants and so on. You should gradually increase your integration so that after three months, you are socializing normally.

- Wear thick protective gloves when gardening, especially when dealing with soil because of the infection risk.
- Avoid excessive exposure to sunlight, as your skin is more sensitive because of the medications you are taking, and this will put you at more risk of skin cancer. Use a sunblock, we recommend Factor 50 with UVB protection. Avoid sunburn because this will increase your risk.
- Avoid areas of construction – for example, building sites – if possible, due to an increased risk of airborne fungal infection.
- Raise the head of your bed with 4-inch blocks under the feet at the head of the bed. Having the bed at this angle will reduce the risk of heartburn.

### ***Religious Support***

Healing involves caring for you as a whole person and meeting your needs, not just on the physical level, but also on the spiritual and religious levels. With this in mind, we offer you the services of the pastoral care team. We aim to help all faith traditions.

The members of our ecumenical pastoral care team are chaplains from the main Christian traditions. We also liaise with leaders of other faiths.

We try to meet your religious, spiritual and cultural needs while you're in hospital. The local priest and minister visit the ward regularly. Please let us know if your religious needs are not being met.

### ***Publicity***

Transplantation is no longer headline news. However, your particular situation may attract media attention. If this is the case, and you are happy for the media to report your story, a daily update on your condition will be kept in the public relations office. Information about you will never be issued without your consent.

**Permission for media personnel to enter the hospital must be obtained from the hospital management.**



## **Social Media**

Organ donation is a generous decision made by donor families on the understanding that the process in Ireland is confidential. Please respect that confidentiality.

- Never be precise about the date of your transplant.
- Do not post news about your transplant operation on social media.
- Do not ask about your donor or try to find out about them or the circumstances of their death.

It is important to be respectful of this so that the transplant programme continues to grow and benefit many more people.



*The lung transplant team receiving Irish Healthcare Centre Award for best small clinical team 2017.*

## Writing to the donor family

Once you have recovered from your transplant, you might begin to wonder about your donor. Even more importantly, you may begin to think about the family of your donor. At some stage following your transplant, you may wish to find some way to thank this family.

Deciding to write to a family is a very personal decision. Some people simply send a thank you card; others wish to write a longer letter. There is no right or wrong thing to do or say. If you decide to write to the family, the letter should be sent to a member of the transplant team who will forward it. You will only get very limited, general information about your donor. Likewise, only general information will be given to the donor family about you. We have produced a leaflet called "Writing to your Donor Family" to help you.

Whatever you decide, the transplant team are there to support you.



*Andy Kavanagh and David Crosby with Debbie Byrne (Managing Director of An Post Retail) at the launch of the An Post stamp promoting organ donation 2019.*

*The stamp features an hourglass timer to represent the precious nature of time and the gift of life passing from one person to another through organ donation .*

*Photo courtesy of An Post/Maxwells Photography*

## Section 5: Acknowledgements

We wish to express thanks to all the members of the transplant team, past and present, who have worked on the adaptation of this Lung Transplant Information Booklet for the Mater Misericordiae University Hospital.

Clinical Photography took many of the photos used and staff included are aware that their images are used here.

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We particularly wish to thank the patients who, through the Mater Foundation, funded the editing, typesetting and printing of this book. Particular thanks also to the patients who reviewed the text and provided helpful suggestions, particularly Mr Ed O'Callaghan, Mr Paddy O'Mahony and Ms Maria Delaney.



*Celebrating with Vera Dwyer in recognition of her achievement. She had a single lung transplant 30 years ago and is in the Guinness book of records.*



We would also like to remember Denise Commins, talented artist and lung transplant recipient.

The use of her painting on the cover is by kind permission of her family.

## Appendix 1 – Medication after transplant

This section contains more information about the medications that are used after transplant. The pharmacist will give you more information. Take the time to read the leaflets that are included with the medication – if you are concerned about anything you read in the leaflet or if it seems to contradict something that we told you, please check with us.

### 1. Ciclosporin (Neoral®) (pronounced “SYE-kloe-SPOR-een” or Tacrolimus (pronounced “tak-ROE-li-mus”) (Prograf®)

(The name with ® is the brand name of the medicine).

These are immunosuppressive drugs which require regular blood tests to check the level in your blood. The dose is then adjusted to suit you personally over a period of time. It is important that you take it exactly as you have been instructed.

You will be taking one of these two medications. You must stay on the same brand unless the transplant team change it. This is because different brands may be absorbed in the body differently.

The dose is taken twice daily at twelve-hourly intervals – 10 o'clock in the morning and 10 o'clock at night.

**Here is some information to remember when you're taking either of these drugs.**

- There are several strengths available so that your dose can be adjusted. Be careful to take the correct dose, as the packaging may look similar.
- Food can affect the way your body absorbs these medications. You may take these medications with or without food, but it is important that you are consistent. In other words, if you normally take the drug with food, always take it with food. If you usually take Creon® (a drug to help digestion), we may ask you to take some Creon at the same time to improve absorption.
- If your stomach is not working well, we may advise you to open the Prograf drug capsules and put the powder under your tongue. Do not do this without being specifically instructed to do so.
- The capsules are stored in a protective foil covering. Do not remove the capsule from the foil until you are ready to take it.

## **2. Mycophenolate Mofetil /Mycophenolic Acid (pronounced "MYE koe FEN oh late MOF e til")**

**Mycophenolate mofetil is an immunosuppressive drug.**

The capsule or tablet should be swallowed whole, and taken twice daily at twelve-hourly intervals – 10 o'clock in the morning and 10 o'clock at night unless you are told otherwise.

If you have a stomach upset try taking this medication with food. There are different brands of mycophenolate mofetil available for example Mycolat® and Cellcept®. It is OK to take different manufacturers' brands.

## **3. Azathioprine (Imuran®) (pronounced "ay za TIE oh preen")**

Azathioprine is an immunosuppressive drug.

Azathioprine is available as a branded preparation called Imuran® it is not important what brand that you take.

Azathioprine is usually taken once a day, with or after food to reduce the chance of stomach upset.

A medicine used to prevent gout, called allopurinol, interacts with azathioprine, so, when used together, your azathioprine dose will need to be reduced a lot by the transplant team.

## **4. Steroids**

### ***Prednisolone***

Prednisolone is usually taken as a single dose in the morning with or after breakfast. This helps to reduce the risk of stomach irritation. The dose will be high at the start, but will be reduced every few days or every week.

You must never suddenly stop taking prednisolone – and never run out of tablets.

Steroids are sometimes given by injection to treat severe rejection symptoms.

## 5. Anti-infectives/antibiotics

The immunosuppressive drugs help to stop your body from rejecting your new organ, but they also make you less able to fight infections. To prevent various infections occurring, we use a combination of medicines. They are described below.

### **Co-trimoxazole (Septrin ®)**

Co-trimoxazole is used at a low dose to prevent a type of pneumonia called 'pneumocystis'. You should take this as directed by the transplant team. Usually, co-trimoxazole is a life-long treatment.

### **Colistin (pronounced co LIST in)**

You may be started (or restarted) on colistin through a nebuliser to reduce the amount of bacteria in your lungs. It is very important that you make time to take this medication twice daily as prescribed. You may not use the nebuliser you had before the transplant as this can lead to re-infection of your lungs. You will have to get a new nebuliser and you may have to pay for this yourself.

### **Azithromycin (pronounced a ZITH roe MY sin)**

This antibiotic has many uses and can improve lung function and help to prevent rejection.

### ***Antivirals***

Antivirals may only be needed for a few months after transplant to reduce the risk of viral infection. The transplant team will tell you when you can stop taking them.

### ***Mouth Care***

The mouth contains bacteria which can infect the lung, so it is important to follow good practice for mouth care. This will help to reduce the spread of bacteria into your lung.

### **Chlorhexidine Mouthwash**

Chlorhexidine is used to help prevent, and treat, infections of the mouth and helps stop plaque forming on your teeth. You can continue using this all your life if you wish.

## **Nystatin Drops**

Nystatin drops are used to prevent fungal infections (thrush). You should swish it around the mouth and then swallow it. It is usually discontinued a few months after transplant. You should use it after chlorhexidine mouthwash so that the medicine works in your mouth for longer.

## ***New Medications***

Transplant medications are very powerful and can have several unwanted side-effects. Some patients develop high blood pressure, diabetes or osteoporosis as a result of the medication. You may have to start new medications after transplant to prevent or treat these complications.

## ***Laxatives***

It is very important to avoid constipation as it will affect the way your medications work and put you at risk of rejection and kidney problems. It will also make you feel sick. If you notice that you are getting constipated, contact the clinic for advice and start your usual laxatives.

