

## CDI Clinical Designs - Cover Sheet\*

Document Type	Model of Care
Document Title	Cystic Fibrosis and Lung Transplantation in Adults - A Model of Care
Document Owner (e.g. NCP)	NCP Cystic Fibrosis
NCAGL	NCAGL Acutes
Approved by	CCO Forum
Unique Identifier Number (UID)	CDI/0218/1.0/2025
Version Number	1
Publication Date	2022
Recommended Revision Date **	April 2028
Electronic Location	

*\*National Clinical Guidelines must use NCR cover sheet if being uploaded onto NCR. Otherwise this cover sheet applies*

*\*\* Refer to [HSE National Framework for developing Policies, Procedures, Protocols and Guidelines \(PPPGs\)](#)*

Version	Revision Date	List Section Numbers Changed	Author
1.0	2025	No Change	



***tE*** ROYAL  
COLLEGE OF  
PHYSICIANS  
OF IRELAND

# **Cystic Fibrosis and Lung Transplantation in Adults**

**A Model of Care for Ireland**

**National Clinical Programme For Cystic Fibrosis**

## Contents

Membership of NCPCF Working Group	i
Membership of NCPCF Cystic Fibrosis and Lung Transplantation Subgroup	ii
Abbreviations	iii
Foreword by Cystic Fibrosis National Clinical Lead	iv
Executive Summary	v
1. Introduction	1
2. Lung Transplantation Referral Guidelines	2
3. Cystic Fibrosis Lung Transplantation Referral Recommendations for Ireland	2
4. Irish Lung Transplant Referral Standards	4
5. Transitioning to Lung Transplant	4
5.1 General Considerations at Time of Transplant Referral	4
5.1.1 Medical	4
5.1.2 Psychology	5
5.1.3 Pharmacy	8
5.1.4 Dietetics	9
5.1.5 Physiotherapy	9
5.1.6 Microbiology	10
5.1.7 Medical Social Work	11
5.1.8 Communication	12
5.2 Lung Transplant Referral Process	14
5.3 Standards	16
6. Post-Lung Transplantation Model of Care	17
6.1 Potential Models	17
6.2 Recommended Models	18
6.3 Special Situations	20
7. References	22
Appendix 1: Transplant Information Sheet for PWCF	23
Appendix 2: Referral document to the Transplant Centre	27
Appendix 3: MMUH CF MDT Referral Information for Transplant MDT	34
Appendix 4: MMUH Heart / Lung Transplant Assessment Checklist	42
Appendix 5: HSE recommendation on Vaccination in the Immunocompromised	46

## Membership of NCPCF Working Group

Ms June Boulger	National Lead, Patient and Public Partnership, AHD
Ms Eileen Burke	Nominee from HSE Acute Hospitals Division (from Q3 2016)
Ms Patricia Duffy Barber	Nominee from Cystic Fibrosis Ireland
Mr Godfrey Fletcher	Nominee from the Cystic Fibrosis Registry of Ireland
Prof Charles Gallagher (Chair)	National Clinical Lead, NCPCF
Ms Helen Gibbons	Nominee from the Psychological Society of Ireland
Ms Ruth Hannon	Nominee from the Irish Nutrition and Dietetic Institute
Dr Mary Herzig	Nominee from Saolta Hospital Group
Dr Howard Johnson	Clinical Lead, Health Intelligence R&D HSE
Mr Gary Killeen	Programme Manager, NCPCF
Dr Ann Leahy	Nominee from CF Shared Care Centres
Ms Gerardine Leen	Nominee from Office of Nursing and Midwifery Services Director
Dr Barry Linnane	Nominee from University Limerick Hospitals Group
Dr Sinead McDermott	Nominee from the Irish Society of Clinical Microbiologists
Prof Gerry McElvaney	Nominee from RCSI Hospitals Group
Prof Edward McKone	Nominee from the Cystic Fibrosis Registry of Ireland
Prof Paul McNally	Nominee from the Children's Hospital Group
Ms Geraldine Nolan	Nominee from the Irish Association of Respiratory Physiologists
Prof Barry Plant	Nominee from South/Southwest Hospital Group
Ms Clare Reilly	Nominee from the Irish Society of Chartered Physiotherapy
Dr Eoin Tiernan	Nominee from Palliative Care Consultants
Mr Philip Watt	Nominee from Cystic Fibrosis Ireland

## Membership of NCPCF Cystic Fibrosis and Lung Transplantation Subgroup

Ms June Boulger	National Lead, HSE National PWCF Experience Survey
Ms Lydia Cullen	CF Physiotherapist, Beaumont Hospital Adult CF Centre
Ms Maria Delaney	Person with Cystic Fibrosis Post-Transplant
Ms Jo Doyle	CF Nurse Specialist, St. Vincent's University Hospital Adult CF Centre
Mr Godfrey Fletcher	Chief Executive Officer, Cystic Fibrosis Registry of Ireland
Prof Patricia Ging	Transplant Pharmacist, National Heart and Lung Transplant Unit, Mater Misericordiae University Hospital
Prof Margaret Hannan	Transplant Microbiologist, National Heart and Lung Transplant Unit, Mater Misericordiae University Hospital
Ms Ruth Hannon	CF Dietitian, Beaumont Hospital Adult CF Centre
Mr Gary Killeen	National Programme Manager, National Clinical Programme for CF
Ms Caitriona McGrath	CF Nurse Specialist, University Hospital Limerick Adult CF Centre
Prof Edward McKone	CF Consultant, St. Vincent's University Hospital Adult CF Centre (Co-Chair)
Dr Michael O'Mahony	CF Consultant, Galway University Hospital Adult CF Centre
Dr Michelle Murray	Transplant Consultant, National Heart and Lung Transplant Unit, Mater Misericordiae University Hospital
Ms Catherine McKeown	CF Psychologist, St. Vincent's University Hospital Adult CF Centre
Prof Barry Plant	CF Consultant, Cork University Hospital Adult CF Centre (Co-Chair)
Dr Ruth O'Reilly	CF Consultant, CHI at Crumlin Paediatric CF Centre
Ms Elizabeth Watson	CF Medical Social Worker, St. Vincent's University Hospital Adult CF Centre

## Abbreviations

6MWT	Six Minute Walk Test
ABG	Arterial Blood Gas
BMI	Body Mass Index
CF	Cystic Fibrosis
CFRI	Cystic Fibrosis Registry of Ireland
CHI	Children's Health Ireland
CME	Continuing Medical Education
CPD	Continuing Professional Development
ENT	Ear, Nose and Throat
FEV <sub>1</sub> pp	Forced expiratory volume in one second percent predicted
GI	Gastrointestinal
HLA	Human Leukocyte Antigen
HSE	Health Service Executive
ICU	Intensive Care Unit
LTx	Lung Transplantation
MDT	Multi-Disciplinary Team
MMUH	Mater Misericordiae University Hospital
MSW	Medical Social Worker
NCPCF	National Clinical Programme for Cystic Fibrosis
PFT	Pulmonary Function Test
PWCF	Person / People with Cystic Fibrosis

## Foreword by Cystic Fibrosis National Clinical Lead

This Model of Care for “Cystic Fibrosis and Lung transplantation in Adults in Ireland” was written by the NCPCF Cystic Fibrosis and Lung Transplantation Subgroup and was reviewed, revised, and approved by the NCPCF Working Group. I am very grateful to the Subgroup and the Working Group for their hard work and dedication in writing this Model of Care.

The NCPCF is also very grateful to Dr Néidín Eustace, Ms Maria Love, Ms Sandra Murphy, Ms Susan Talbot Towell and Ms Julie Winters of the National Heart and Lung Transplant Unit Mater Misericordiae University Hospital for their comments on, and input into, this Model of Care

I want to acknowledge the very strong support, guidance, and wisdom that I received from Dr Colm Henry, HSE Chief Clinical Officer; Dr Siobhán Ni Bhriain, HSE National Clinical Director, Integrated Care; and Dr Mike O Connor and Dr Vida Hamilton, the current and previous National Clinical Advisor and Group Lead, HSE Acute Hospitals Division. I am very grateful to Prof Mary Horgan, President RCPI and Dr Amir Niazi, National Clinical Advisor and Group Lead for Mental Health for their strong support. I am very grateful to Ms Elaine Brown, Portfolio Manager, HSE Acute Operations, for her wisdom and guidance. I want to specially thank Mr Gary Killeen, NCPCF Programme Manager, for all his untiring work and dedication.

This Model of Care is dedicated to People with Cystic Fibrosis, and their families, who bravely deal with CF every day of their lives. It is also dedicated to the People with Cystic Fibrosis who are no longer with us and their families; you are not forgotten.

Professor Charles Gallagher

National Clinical Lead, National Clinical Programme for Cystic Fibrosis

## Executive Summary

'Cystic Fibrosis: A Model of Care for Ireland' was published by the National Clinical Programme for Cystic Fibrosis (NCPCF) and the HSE, and was launched by the then Minister for Health, Simon Harris in September 2019. It outlines how the care of People with Cystic Fibrosis (PWCF) should be organised and resourced now and in the future.

That Model recommended the preparation of a specific Model of Care dealing with cystic fibrosis and lung transplantation. Therefore, the NCPCF Cystic Fibrosis and Lung Transplantation Subgroup developed this Model of Care which outlines how lung transplantation fits into the continuum of care of Adults with Cystic Fibrosis; this includes referral, assessment, listing and communication regarding transplantation and post-transplant care. This Model is an extension of, and should be implemented in conjunction with, 'Cystic Fibrosis: A Model of Care for Ireland'.

This Model of Care was written by the NCPCF Cystic Fibrosis and Lung Transplantation Subgroup and was then reviewed, revised, and approved by the NCPCF Working Group. The Subgroup is co-chaired by Prof Ed McKone and Prof Barry Plant and its membership includes representatives from the National Heart and Lung Transplant Unit at the Mater Misericordiae University Hospital (MMUH), a PWCF Post-Transplant and members from different CF Centres and disciplines involved in the care of PWCF.

This Model of Care details seven phases in the process of lung transplantation from consideration for lung transplantation to post-transplantation care. It makes specific referral recommendations for CF lung transplantation in Ireland including that:

- CF Teams should initiate discussion regarding lung transplantation with all PWCF whose lung function (forced expiratory volume in one second, FEV<sub>1</sub>) is less than 50% predicted. Written information regarding lung transplantation should also be provided, after the discussion, unless the PWCF does not want it
- For all PWCF attending an adult CF centre, lung transplant referral is recommended no later than when:
  - FEV<sub>1</sub> is < 50% predicted and rapidly declining (>20% relative decline within 12 months)
  - FEV<sub>1</sub> is < 40% predicted with any marker of shortened survival.
  - FEV<sub>1</sub> is < 30% predicted
- Referral for lung transplant assessment may be considered for Females with PWCF or PWCF with short stature, even when other thresholds have not been met.
- Some PWCF may have modifiable barriers to lung transplantation. Where possible, these should be addressed early to optimize transplant candidacy.

The management of PWCF being considered for lung transplant will remain under the care of the referring CF team until the time of lung transplantation.



Effective communication regarding transplantation is an essential part of care of PWCF. This 3-way communication must involve PWCF and their families, the CF Team and the MMUH Transplant Team. It is recommended that the relationships between the Transplant Team and the CF teams continue to be strengthened, including regular multidisciplinary meetings.

The transplant process as a whole, including referral, assessment, listing and waiting for transplant, adds to the ongoing physical and psychological demands that PWCF and their families face. It is crucial that every CF Centre should have an appropriately staffed multidisciplinary CF team dedicated to the care of PWCF. Otherwise, timely early referral for transplant assessment will not be possible. It is also crucially important that each PWCF is at the centre of communication regarding their health, including the transplantation process.

The majority of morbidity and mortality of PWCF post-transplantation is related, directly or indirectly, to transplant-related issues. However, some PWCF continue to have significant extrapulmonary disease, related to CF. This Model of Care recommends the establishment of two pathways to address the specific needs of PWCF post-transplant in Ireland.

- PWCF who live reasonably close to the MMUH (in the Leinster area) will receive both their post-transplant care and CF-related care from MMUH.
- PWCF who are geographically distant from MMUH will receive their post-transplant care jointly from the local CF Centre and MMUH, and their CF care from the local CF Centre.

These pathways will result in both the MMUH, and the CF Centre being designated as Post-Transplant CF Centres. It is very important to the success of this model that they be appropriately resourced to carry out these roles.

Lung transplantation is rarely needed in children with CF but is an important issue. For Irish PWCF, paediatric transplant surgery takes place in the United Kingdom with follow-up shared between the United Kingdom and Ireland. The NCPCF recommends the development of a separate policy document dedicated to Cystic Fibrosis and Lung Transplantation in Children

## 1. Introduction

The National Clinical Programme for Cystic Fibrosis (NCPCF) and the HSE published "Cystic Fibrosis: A Model of Care for Ireland" in 2019. It outlines how the care of People with Cystic Fibrosis (PWCF) should be organised and resourced now and in the future. This current Model of Care outlines how Lung Transplantation fits into the continuum of care of Adults with Cystic Fibrosis; this includes referral, assessment, listing and communication regarding transplantation and post-transplant care. Therefore, the current Model is an extension of, and should be implemented in conjunction with, "Cystic Fibrosis: A Model of Care for Ireland".

Cystic Fibrosis is the most common genetic condition that causes progressive respiratory disease resulting in significant morbidity and early mortality. Median survival in CF is currently in the mid-50s, with respiratory failure the most common cause of death<sup>1</sup>. Although there have been substantial improvements in CF care and survival over the last decades, lung transplantation (LTx) is an important treatment option for PWCF with severe lung disease. However, internationally many PWCF die without being referred or assessed for lung transplantation. Although there are multiple reasons for this, it is clear internationally that some PWCF may benefit from LTx, who are not being considered eligible or are being referred too late. Early lung transplant referral allows modifiable barriers to transplant to be addressed and if transplant is not an option, alternative management strategies can be considered such as palliative care as lung disease progresses. For PWCF in whom LTx is an option, care of these PWCF as they transition through the process of transplant assessment, listing, surgery, and post-transplant care is not standardised internationally; clear recommendations regarding these steps before and after LTx are important to ensure that the difficult transition to LTx is as smooth as possible and to optimise post-transplant outcomes. Developing sustainable care models for LTx in PWCF is an emerging area, demonstrated by the recent publication of a small number of guidelines and consensus statements<sup>2-4</sup>. A fully functioning lung transplant programme has evolved in Ireland since 2012 and now caters for all adults with CF requiring lung transplantation. With the developments and opportunity of lung transplantation in Ireland, a cohort of critically ill PWCF requiring multidisciplinary inpatient and outpatient care can bridge to successful transplant and subsequently post-transplant management<sup>4</sup>. The Mater Misericordiae University Hospital (MMUH) is the National Heart and Lung Transplantation Centre for Ireland. The MMUH lung transplant programme, including PWCF, commenced in 2005. Since 2012 all LTx for adults with CF are undertaken in MMUH. Prior to 2012, some LTx were undertaken in the Freeman Hospital in the UK. The number of CF post lung transplant recipients attending MMUH is 101 (MMUH, 2021) and MMUH is the main centre for post-transplant care in Ireland, On the basis of the numbers of existing PWCF; the predicted increase in the CF adult population in Ireland in forthcoming years; the complexity of post TX care, including palliative care it is crucial that

the necessary clinical and related resources are regularly assessed and provided to meet the needs of PWCF who are pre and post-transplant.

All adult PWCF who are being considered for lung transplantation are referred to MMUH and all PWCF post-transplant are currently managed by MMUH, with some co-managed by their local CF centre. To date, there are no models of care for the PWCF who are being considered for and undergo LTx. Recently, the US Cystic Fibrosis Foundation published lung transplant referral guidelines for PWCF which is an important document and highlights criteria for appropriate timing of referral for LTx <sup>3</sup>. There are no consensus guidelines currently available for the transition from referral through to post-transplant care. This document has been developed by the HSE National Clinical Programme for Cystic Fibrosis to establish a model of care for Cystic Fibrosis and Lung Transplantation including timing of referral, LTx assessment and transition through transplant to post-transplant care for PWCF in Ireland.

Transplant care for PWCF is a continuously evolving area and this document sets a solid foundation which will require intermittent review in the future.

## **2. Lung Transplantation Referral Guidelines**

The Cystic Fibrosis Foundation lung transplant referral guidelines for PWCF recognise that internationally some PWCF who might be eligible for transplant die from respiratory failure without being referred or assessed for transplantation; these guidelines provide clear recommendations as to when transplant referral should be considered <sup>3</sup>. Pathways to recognise PWCF at risk of rapid decline have also been identified and CF centres are encouraged to refer PWCF to Transplant Centres early if there are concerns regarding rapid disease progression. These recommendations are a guide and there may be cases of PWCF who require earlier referral. In these cases, the CF Centre should contact MMUH directly to discuss.

## **3. Cystic Fibrosis Lung Transplantation Referral Recommendations for Ireland**

1. It is recommended that CF Teams should initiate discussion regarding lung transplantation with all PWCF whose lung function (forced expiratory volume in one second, FEV1) is less than 50% predicted. Written information regarding lung transplantation should also be provided, after the discussion, unless the PWCF does not want it (Appendix 1).
2. Referral for transplant does not always require full assessment at the transplant centre and could be carried out in the local CF centre. The form in Appendix 2 is the only form that is required to be completed
3. Up-to-date Irish CF-specific transplant resources should be used to promote understanding of the transplant journey and to minimise misconceptions regarding outcomes.
4. It is recommended that CF teams involved in the transplant referral process develop relationships including regular multidisciplinary meetings with their peers at the Mater

Misericordiae University Hospital (MMUH) National Lung Transplantation Centre. For transplant candidates, frequent communication including virtual MDT meetings between the CF and lung transplant care teams at least every 3 months or after any major clinical change are recommended.

5. Modifiable barriers to lung transplantation including psychosocial and physical concerns about lung transplantation should be addressed pre-emptively to optimise transplant candidacy; however, unresolved barriers should not preclude referral.
  - a. In selected cases where there is uncertainty regarding eligibility or modifiable barriers to transplant, early consultation with the transplant team, without full pre-transplant assessment, is recommended.
  - b. Full assessment should only be done after the lung transplant team have reviewed the PWCF first, and they recommend it. If full assessment is required, additional investigations, and MDT reports as outlined in Appendix 3 should be provided. The referring team should complete both. The MMUH Heart / Lung Transplant Assessment Checklist can be found in Appendix 4.
6. Lung transplant evaluation, regardless of FEV1pp, is recommended when there are markers of shortened survival including: 6-minute walk test (6MWT) distance < 400 meters, hypoxemia (at rest or exertion), hypercarbia, or pulmonary hypertension.
7. For PWCF attending an adult CF centre, lung transplant referral is recommended no later than when:
  - i. FEV1 is < 50% predicted and rapidly declining (>20% relative decline within 12 months)
  - ii. FEV1 is < 40% predicted with any marker of shortened survival.  
 These markers include:
    - massive haemoptysis (>240 mL) requiring intensive care unit (ICU) admission or bronchial artery embolisation.
    - Pneumothorax
    - any exacerbation requiring positive pressure ventilation.
    - ≥3 exacerbations per year requiring intravenous (IV) antibiotics.
    - a body mass index (BMI) < 18kg/m<sup>2</sup>
  - iii. FEV1 is < 30% predicted
8. For PWCF with an FEV1 <40% predicted, an annual 6MWT and/or CPET is recommended as well as an assessment of need for supplemental oxygen, and venous blood gas to screen for markers of severe disease that may warrant transplant referral.
9. For PWCF attending an adult CF centre, with FEV1 < 40% predicted, a baseline echocardiogram to screen for pulmonary hypertension is recommended.

10. For PWCF with short stature (height <162 cm) and FEV1pp<50%, lung transplant referral can be considered even when other thresholds have not been met.
11. For females with CF, especially those who are younger, lung transplant referral should be considered in selected cases that are deteriorating rapidly even when other thresholds have not been met.

#### 4. Irish Lung Transplant Referral Standards

1. All PWCF with FEV1<50% predicted should have the topic of lung transplantation discussed with them by their CF team and if requested, be provided with written information on lung transplantation (See Appendix 1).
2. All PWCF with FEV1<50% predicted should have investigations to identify if they may be at risk of rapid decline and need early consideration for lung transplant assessment.

#### 5. Transitioning to Lung Transplant

Being referred for lung transplantation assessment can be a difficult experience for PWCF who, by definition, have severe lung disease. PWCF must be supported throughout the referral process especially at the start when the recommendation for transplant referral is made, as some PWCF may feel that the referral time is early. Likewise, once referral is made, it is important that the referral process takes place in a timely manner and that communication between the MMUH and referring CF centre is optimal. Discussion regarding lung transplantation may be started earlier in selected PWCF in order to normalise the discussion while being mindful not to exacerbate fears about disease trajectory. To reduce concerns about disease status, a CF-specific lung transplant information sheet has been developed and should be shared with all PWCF at time of transition from the Paediatric to the Adult Cystic Fibrosis Centre. This is included in Appendix 1.

PWCF will be given a comprehensive Lung Transplant Information Leaflet at the time of referral for lung transplant. This is available at: <https://www.mater.ie/services/heart-and-lung-transplant/>

#### 5.1 General Considerations at Time of Transplant Referral

##### 5.1.1 Medical

- i. The management of the PWCF being considered for lung transplant will remain under the care of the referring CF team up until the time of lung transplantation
- ii. The CF Consultant and Clinical Nurse Specialist will co-ordinate the transplant referral and the transplant process, including education regarding the transplant pathway.
- iii. PWCF with potential barriers to lung transplantation may benefit from early discussions with MMUH to ensure that, as disease progresses, these barriers do not preclude lung transplantation. In these cases, early referral to the MMUH is recommended. These PWCF

do not require a full transplant assessment and can be referred with a minimum dataset and a detailed referral letter, listing the specific transplant related questions for the transplant team.

- iv. Minimum dataset for initial review of PWCF who are being referred early for discussion of modifiable barriers are:
  - a. Full PFTs, 6MWT, Echocardiogram, ABG, complete microbiology history, recent CT scan, oxygen therapy and non-invasive ventilation usage.
  - b. Referral form listed in Appendix 2 including specific questions to be addressed by Transplant team.
- v. For PWCF meeting criteria for Formal Transplant Referral, investigations for Full Transplant Assessment are listed in Appendix 3.

### 5.1.2 Psychology

We strongly recommend that all CF Centres have Senior or Clinical Specialist CF Psychologists dedicated to the care of PWCF, as recommended in Cystic Fibrosis A Model of Care for Ireland (2019). In centres that have a CF psychologist, psychological assessment is an important part of the pre-transplant workup. For centres that do not yet have a CF psychologist, this will be part of the transplant process after referral to MMUH.

**Pre-transplant psychological assessment** must involve a multidisciplinary team approach to assess the PWCF's abilities to navigate the complexities of the transplant process and to cope with pre and post-transplant life. Pre-transplant psychosocial assessment is necessary to provide an in depth knowledge of the candidate, the family, and supporters and to explore any underlying fears or mental health issues.

The pre-transplant psychosocial evaluation involves the Senior CF Psychologist and in selected cases, liaison psychiatry support, who will address the following areas:

- Personal History
- Attitude to illness and transplantation
- Readiness for transplant
- Health Literacy Optimisation
- Self-efficacy
- Quality of life
- Anxiety
- Depression
- Coping
- Resilience

- Adherence and previous history with compliance would need to be disclosed and explored
- Cognitive function and mental state
- Current additional symptoms
- Psychiatric history – candidate's and family history
  - History of self-harm
  - Psychosis
- Substance use
- Psychotropic Drug use
- Social supports
- Significant intellectual disability

A CF-specific Bio–Psycho–Social–Assessment will facilitate the initial assessment process. Prior to referral and after transplant has been raised with the PWCF it is important to assess:

#### **Attitude to illness & transplantation**

- Is the PWCF sufficiently informed about the transplant procedure and the aftermath of surgery and post-transplant living?
- Do the PWCF and family/supporters appreciate the transplant process and the demands it places on all involved?
- Are transplantation expectations realistic?
- What does PWCF hope to gain from transplant?
- Are they aware of complications, immunosuppression, and side effects of medications used post-transplantation?

#### **Readiness for transplant**

- Is the PWCF aware that transplant is a very demanding and stressful event that requires the application of bio-psychosocial skills to help the candidate both physically and mentally?
- Is the PWCF aware of the psychological and physical effects of surgery
- Is it recognised that there is also a process of emotional and psychological transplant integration?
- Individuals will be supported to:
  - Accept and integrate their new lungs and move forward with life.
  - Embrace wellness and planning for the future.
  - Realise that transplant is a treatment option and not a cure.

## Health literacy

Each candidate must have:

- An ability to read and understand medical information.
- The ability to complete medical forms.
- An understanding of medicine dosages and relevant laboratory values and adherence to medication and treatment regimens.
- The ability to communicate properly and effectively with the Cystic Fibrosis and Transplant teams.

## Waiting on active lung transplant list

Going on an active lung transplant wait list can be overwhelming. PWCF will have to be physically and emotionally ready for the commitment before the recommendation will be to list. PWCF will also have to remain physically active and nutritionally well to remain suitable for transplant or they could be suspended from the list. PWCF will require support during times of illness and PWCF also worry about the uncertainty and when or if suitable donor organs will be available. PWCF may also, while they are on the active lung transplant list, get a "false call", when they are called in for a prospect of a transplant, but the transplant does not go ahead due to unsuitability and often PWCF will experience disappointment and upset when that happens and will need to be supported by the CF and transplant teams.

The role of the psychologist is to help the PWCF cope with the emotional stressors associated with waiting for transplant. This will involve facilitating change and stress reduction through counselling and addressing the PWCF's difficulties, such as adjustment to illness (deteriorating health), fear of uncertainty, grief, anxiety and depression, feelings of helplessness and hopelessness, frustration, preoperative fear, and fear of death. An important element is addressing adherence issues or phobias that should be explored and disclosed to the transplant team

The psychologist will devise psychological interventions to:

- Facilitate illness acceptance
- Cope with the losses and disappointments associated with chronic illness and waiting for transplant
- Improve adherence working with the wider MDT
- Facilitate better decision making
- Facilitate coping strategies
- Help with reframing
- Assess for changes in anxiety and depression symptoms and consult with liaison psychiatry as appropriate



- Challenge unrealistic goals and expectations and remind the PWCF to remain present centred
- Introduce relaxation techniques – mindfulness exercise and distraction techniques to help with high levels of anxiety and stress reduction
- Encourage the PWCF to be more solution focussed and to problem solve, as this will give them a sense of mastery over their illness
- The psychologist plays a pivotal role in the communication process and encourages the PWCF to communicate with their CF MDT, transplant team, and family as information helps empower the PWCF to make good decisions and reduce feelings of stress and worry

At time of referral to MMUH, the following psychology information is provided:

- Detailed report from psychologist outlining issues to date including transplant readiness as outlined above.
- Any reports completed or if the PWCF has had any cognitive assessments (this won't apply to everyone)

In all instances, practice must be aligned with the HSE national consent policy.

### 5.1.3 Pharmacy

A detailed medication history is critical to the transplantation transition process. At time of referral to MMUH, the following medication history is required:

- Current list of medications and doses. This needs to be updated when changes are made. This includes vitamins, herbal and alternative medications, and contraception.
- Allergies - particularly allergies to antimicrobials. Information should be explicit about the nature of the allergy and anything which has been successfully used to aid tolerability of the agents e.g., slower titration, antihistamine cover, desensitisation.
- Drug intolerance - particularly intolerance to antimicrobials. Information should be explicit about the nature of the side effects and anything which has been successfully used to aid tolerability of the agents e.g., slower titration, reduced dose or anti-emetic use etc.
- Current "best" antimicrobial regimen including doses, needs to be updated if it changes. This should be included in all discharge communications and copied to MMUH.
- Assessment of adherence to medications. Following transplant, adherence to medications needs to be 100%, in particular to immunosuppression, antimicrobials, insulin, nebulisers, and GI medications.
- If the candidate has osteoporosis/osteopenia, please state date that treatment was started and monitor effect.

#### 5.1.4 Dietetics

Information required for transplant dietetics assessment are included in the MDT referral documentation in Appendix 3.

Nutritional status and Body Mass Index (BMI) pre-lung transplantation have been shown to impact survival and post-operative recovery in PWCF. A minimum BMI of  $>17.5\text{kg/m}^2$  is a requirement for listing for lung transplantation. However, optimising BMI closer to the desirable range of  $\geq 22\text{kg/m}^2$  for females,  $\geq 23\text{kg/m}^2$  for males is recommended. Catabolism and wound healing requirements post lung transplantation can result in weight and muscle mass loss post operatively, even in the presence of nutritional support; therefore, optimisation of nutritional status prior to lung transplantation is crucial. Dietetic education and counselling, food fortification, nutritional supplementation and/or supplemental tube feeding may be advisable to help PWCF achieve these targets. However, a BMI of  $>28\text{kg/m}^2$  precludes listing for lung transplantation, and, in an era where newer treatments including CF modulator drugs are associated with weight gain, avoiding excess weight gain is of critical importance in PWCF both prior to and during lung transplant assessment/listing.

Cystic Fibrosis Related Diabetes (CFRD) is increasing in our Irish PWCF population and the requirement for corticosteroids post lung transplant further increases the risk of development of diabetes. Poor glycaemic control can, in turn, lead to poorer outcomes post lung transplantation. Dietetic assessment, education and monitoring of blood glucose levels pre-assessment is key to ensuring PWCF achieve pre-transplant goals, as well as preparing them for the likely increased treatment burden of good blood glucose control post operatively.

Accuracy and adherence to pancreatic enzyme replacement therapy and ensuring aggressive management of constipation and/or Distal Intestinal Obstructive Syndrome are significantly important in optimising nutritional status pre- transplant; however, poor bowel management can affect absorption and metabolism of immunosuppressants which can result in significant complications post-transplant.

#### 5.1.5 Physiotherapy

The physiotherapy referral form is included in Appendix 3

Prior to referral to MMUH:

- i. Rehabilitation and/or prehabilitation is vital for all those being considered for listing for lung transplant. An exercise walking distance of 150m can be considered a target for lung transplantation.
- ii. The CF MDT and transplant teams should address the importance of prehabilitation with all PWCF prior to listing
- iii. The CF Physiotherapist should discuss the importance of exercise as routine care and part of prehabilitation with all PWCF before and after listing for lung transplantation. A good exercise

programme consists of endurance, interval, and resistance training. Walking and using a stationary bike may be recommended in order to maintain the PWCF's fitness levels. The transplant physiotherapists can work with and aid the CF physiotherapists, if necessary, on the optimum exercise that should be done.

- iv. The CF Physiotherapist should be actively involved in the prescription of individualised exercise programs for all PWCF listed for transplant
- v. The CF Physiotherapist should regularly review and modify these exercise programs while the PWCF is awaiting lung transplant
- vi. The CF Physiotherapist should complete a 6MWT at 3 monthly intervals whilst waiting for lung transplant and communicate these results with the Transplant Co-Ordinator

#### 5.1.6 Microbiology

- i. A full review of all previous documented infections is required when considering PWCF for transplant. Initially, a detailed list of all microbiology cultures over the previous 2 years are requested from the transferring hospital, with full visibility on previous microbiology results including full sensitivity of any relevant organisms, information on how frequently respiratory samples (or other relevant samples) were taken and those results. For some PWCF, a more extensive microbiological history may be required.
- ii. Complete vaccination history is required and once PWCF are accepted for transplantation optimisation of vaccine status prior to transplantation will be coordinated such as review of any outstanding boosters or vaccinations can be carried out prior to listing. The vaccination list can be found in Appendix 5.
- iii. Current "best" antimicrobial regimen including doses, to which the PWCF has clinically responded and this needs to be updated if it changes. This should be included in all discharge communications with MMUH.
- iv. Microbiology assessment by CF Transplant Microbiologist also requires review of non-culture microbiological test results (beta-d-glucan, galactomannan etc.)
- v. Full serology assessment and risk for blood borne virus assessment.
- vi. Other relevant health promotion education such as information about avoiding infections in the community etc.
- vii. Antimicrobial stewardship education of PWCF and relevant clinicians in case certain antimicrobials should be avoided pre-transplantation to preserve utility peri transplantation and beyond.

- viii. Allergies - particularly allergies to antimicrobials. Information needs to be explicit about the nature of the allergy and anything which has been successfully used to aid tolerability of the agents e.g., slower titration, antihistamine cover, desensitisation.
- ix. Drug intolerance - particularly intolerance to antimicrobials. Information needs to be explicit about the nature of the side effects and anything which has been successfully used to aid tolerability of the agents e.g., slower titration, reduced dose or anti-emetic use etc.
- x. History of prior fungal infections including investigations, positive and negative results, and treatments.
- xi. History of prior mycobacterium species infection and detailed review of medications received and tolerated. Information should be provided as to whether the PWCF was screened at regular intervals in the referral hospital before referral for Lung transplant.
- xii. Results of recent synergy testing on any multi-drug resistant isolates grown within the last year prior to referral for Lung Transplantation
- xiii. History of colonisation with multi-drug resistant organisms e.g., Carbapenem Producing Enterobacterales, MRSA, and VRE

#### 5.1.7 Medical Social Work

MSW referral forms are included in Appendix 3

- i. The Senior Medical Social Worker in CF (SMSW-CF) will meet with PWCF and explore their wishes, reasons and worries regarding transplant. A summary of this discussion will be shared at the CF MDT.
- ii. The SMSW-CF will invite PWCF to participate in PACT – Psychological Assessment of Candidates for Transplant for sharing with the CF MDT prior to referral for transplant. PACT includes the following domains: Social Support, Psychological Health, Lifestyle factors, Compliance with medications and medical advice and understanding of transplant and follow-up.
- iii. The SMSW-CF will undertake a psycho-social assessment with PWCF to include inviting PWCF to complete a CF specific Bio-Psycho-Social Assessment. (An example of this is the 'About Me' document designed by the CF SMSW and CF Senior Counselling Psychologist in St. Vincent's University Hospital. This document can then be shared (transferred in entirety) with the Transplant Social Worker and Transplant Psychologist).
- iv. The SMSW-CF may accompany PWCF to first meeting with Transplant Social Worker should the PWCF wish.

#### Transition to Lung Transplantation

- i. SMSW-CF will share the Bio-Psycho-Social Assessment with the Transplant Social Worker.

- ii. SMSW-CF will share practical information regarding transplant and transplant support services with PWCF such as grant and financial supports, legal supports, and emotional supports etc.
- iii. SMSW-CF will make referrals to other services as PWCF require.
- iv. SMSW-CF will liaise, share information and co-plan with the CF Senior Counselling Psychologist on an ongoing basis.

#### **On Active List, Awaiting transplant:**

- i. SMSW-CF will provide emotional/practical support to PWCF awaiting transplant.
- ii. Transplant Social Worker will liaise with SMSW-CF quarterly and in between as required.
- iii. Transplant Social Worker will notify SMSW-CF when PWCF is called for surgery.
- iv. Transplant Social Worker to undertake PACT with PWCF during this time.

#### **5.1.8 Communication**

Communication between National Heart and Lung Transplant Unit, MMUH and CF Centres should include:

- i. Virtual CF Transplant MDT should generally be held every 3 months between each referring CF centre and the MMUH National Lung Transplantation Centre; however, the frequency will vary depending on the number of referrals and should be decided between the CF centre and the Transplant centre.
- ii. For any PWCF who is being seen by the transplant team in clinic, the transplant coordinators should be notified within **one week** if there is any significant clinical deterioration of the PWCF with updated history and investigations provided.
- iii. For any PWCF who is actively listed for transplant, the transplant team should be notified **within 24 hours** if there is any significant clinical deterioration of the PWCF and the case will generally be discussed with the Transplant Consultant on call.
- iv. All CF Centre clinic and discharge communications should be copied to MMUH and vice versa.
- v. The MMUH clinic will notify the referring CF centre of any change in transplant status of a PWCF within two working days.

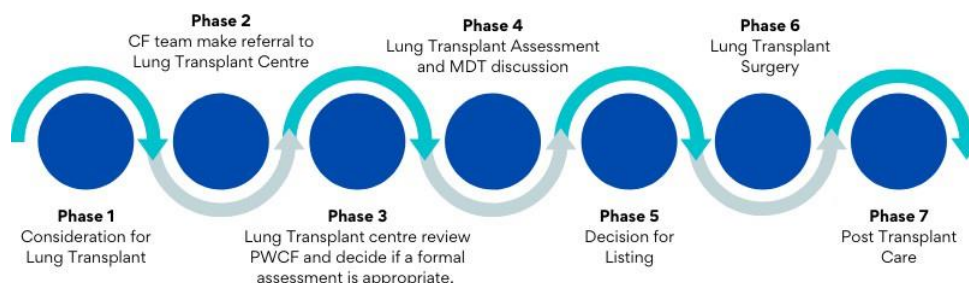
Communication between National Heart and Lung Transplant Unit, MMUH, CF Centres and PWCF should include:

- i. All PWCF with FEV1 < 50% predicted should have the topic of lung transplantation discussed with them by their CF team and, if requested, be provided with written information on lung transplantation

- ii. CF Teams will discuss transplantation process as outlined below with PWCF being considered for transplant. The list of investigation will be provided to the PWCF and rationale for each explained. Results of tests will be discussed with PWCF prior to first attendance in MMUH.
- iii. MMUH will make the final decision on suitability for lung transplant. PWCF and the referring CF service will be informed of outcome of MDT transplant decision within two working days of decision.
- iv. PWCF on the active list will receive communication every week from the MMUH and PWCF will be advised or reviewed earlier if required.
- v. Any change in transplant status should be communicated to the PWCF and the referring CF centre at the same time.

## 5.2 Lung Transplant Referral Process

There are seven phases in the process of lung transplantation. These are shown in figure 1.



*Figure 1 Seven phases of CF lung transplant*

### Phase 1: Consideration for Lung Transplant

This phase will be completed following the outline in Section 1.

### Phase 2: Lung Transplant Referral

PWCF meeting criteria for referral for lung transplantation will be referred using the referral form in Appendix 2. This is the only form that is required to be sent in initially. Referral for transplant does not always require full assessment at the transplant centre and can be carried out in the local CF centre. PWCF with a possible contraindication to transplant should still be discussed with MMUH who will advise whether lung transplantation is suitable for the PWCF.

### Phase 3: Lung Transplant Review Referral

Referral is received by MMUH, and the PWCF is triaged for an outpatient appointment based on information provided. Further information may be required and will be requested by the consultant lung transplant physician.

#### **PWCF will be triaged into Urgent, Soon or Routine appointments**

Urgent PWCF will be seen within 1-2 weeks. Soon will be seen within 4-6 weeks and Routine appointments will be seen within 12 weeks. Referring physicians are advised to call the Transplant Consultant on call if they deem that the referral is urgent and requires early review.

The outcome of the first MMUH appointment will be:

- i. **Proceed to Phase 4:** proceed to assessment and MDT
- ii. **Discharge:** not suitable at all (discharged)
- iii. **Not yet suitable for assessment.** Assessment not required due to modifiable barriers or PWCF is too well (these PWCF may be discussed at the virtual MDTs and the transplant team may be updated).

#### **Phase 4: MMUH Lung Transplant MDT Discussion.**

***Lung Transplant assessment should only be started after review with the transplant consultant at the transplant clinic.***

A checklist of tests is available and additional tests may be requested depending on the PWCF (see Appendix 4). The assessment is undertaken at the CF centre. It is important that when this is completed that the results are sent complete to the transplant team for a review within two weeks of completion. The transplant team once having received the investigations and relevant reports from the CF team will arrange appointments with the surgeons, psychiatrist, and transplant medical social worker. When these are complete, the case will be discussed at the Transplant Assessment MDT and a decision regarding the PWCF's candidacy will be discussed. The outcome of this meeting will be communicated to the referring team and the PWCF within two working days.

Potential outcomes of MDT:

- i. **List** – Offer to PWCF to place on active lung transplant list
- ii. **Not to List** – MDT form is generated, and referring CF Consultant and PWCF are notified, and reasons explained e.g., Unsuitable; contraindications; too well; modifiable barriers; too high risk for transplant.
- iii. **Further information required** – To decide suitability, more information and/ or more tests or consults are required. This should be done in a timely manner.
- iv. **De-listing, suspension, or re-listing** – This will be communicated to the PWCF and the referring CF centre.

#### **Phase 5: PWCF listed for lung transplant.**

This is a critical time where frequent communication between CF centres and MMUH is essential. Any clinical change in the PWCF should be communication to the transplant coordinators on call within **24 hours**. PWCF on the active list who are stable should be discussed at regular scheduled virtual CF Transplant MDT with the MMUH to ensure that the PWCF is ready for transplant.

Certain investigations are required to be updated while on active list. CT/echocardiogram should be repeated at least once a year. Routine blood tests and sputum microbiology should be repeated every 3 months or after an exacerbation. HLA antibodies should be checked monthly. The transplant team will advise of any additional investigations that will be required.

#### **Phase 6: Surgical lung transplant.**

#### **Phase 7: Post-transplant Care (See Section 6)**



## 5.3 Standards

### Referral

1. Once a decision to refer to the transplant centre is made by the CF Team, a referral letter with all required investigations should be completed within 6 weeks (1-2 weeks if urgent and a discussion with the transplant consultant on call).
2. Urgent PWCF will have their first MMUH appointment within 1-2 weeks. PWCF triaged to be seen soon will have their first MMUH appointment within 4-6 weeks, and PWCF triaged as routine will have their first MMUH appointment within 12 weeks.
3. At clinic visit the PWCF is reviewed by the transplant physician and a decision is taken whether to move formally to assessment or not.

### Assessment

4. If a decision is for a transplant assessment, the transplant assessment checklist and investigations should be completed and submitted to the transplant centre within 4-6 weeks (1-2 weeks, if urgent). It should be noted that correspondence with other teams relating to other comorbidities may also be requested.
5. On receipt of the transplant assessment form, the transplant coordinators will list appointments to see other members of the transplant team; urgent cases will be seen within 1-2 weeks of receiving the completed package of tests by the CF referring centre.
6. It should be noted that many PWCF may require additional investigations - GI, ENT etc. The transplant physician will advise on this.
7. The recommended time from receipt of complete transplant assessment package from CF teams to listing decision for lung transplantation should be 4-6 weeks.
8. For urgent transplant referrals, the recommended time from receipt of transplant assessment package by CF teams to listing decision for lung transplantation should be 1-2 weeks.

## 6. Post-Lung Transplantation Model of Care

Worldwide, there is little consensus regarding the management of PWCF after lung transplantation. Most of the morbidity and mortality in PWCF post-transplant is related, directly or indirectly, to transplant-related issues. While it is recognised that some PWCF still have some CF related disease outside of their lungs, the primary focus is with the health of the transplanted lungs and the complications related to immunosuppression and other issues post transplantation. Also, the complex management of acute and chronic rejection, opportunistic infection, immunosuppression, and other long term consequences of lung transplantation such as cancer, requires specialist input from a transplant centre. However, some PWCF continue to have significant extrapulmonary CF disease, and this may be best delivered by a CF MDT who have expertise in these issues.

### 6.1 Potential Models

In order to ensure optimal outcomes for PWCF post-transplant, there are a number of options for post-transplant care. These models should be based on co-operation and partnership between Transplant and CF centres, and recognise the need for expertise in the interaction between lung transplant treatment and CF treatment.

#### **MMUH Transplant Centre as Dedicated Post-transplant CF Centre**

Under this Model, all post-transplant care for CF transplant recipients would be carried out in MMUH as the designated CF post-transplant centre. This includes management of lung transplant related complications, CF related complications and medical issues related to both conditions. Advantages to this model include continuity of care, reduced visits to multiple hospitals and expertise in lung transplant involved in all management decisions. However, for this model to work, it would be essential that the transplant centre is adequately resourced including staffing with expertise in transplant and CF (including the long-term complications of CF) as well as physical resources to ensure that PWCF can be rapidly seen and managed as inpatients and outpatients in a safe environment with appropriate microbiology and infection control resources. If the transplant centre provides all care to the PWCF, the transplant centre should then also be recognised as a NCPCF designated post-transplant CF Centre.

#### **Integrated Shared Care Model**

Under this Model, post-transplant care would be carried out in the transplant centre with all non-transplant related CF care to be provided in CF centres.

Advantages to this are the input from experts in both transplant and CF. However, challenges exist such as multiple teams' involvement in management, visits to multiple hospitals for PWCF, and sometimes

lack of clear distinction between transplant related and CF related conditions. Also, as CF units increase in PWCF numbers and complexity, the additional workload associated with caring for an additional cohort of PWCF post-transplant, in a specific CF centre may not be feasible. For this model to work, there would need to be additional resources, with a need for additional staffing and increase in capital spending.

### **MMUH and CF Centre both as designated CF post-transplant centres**

Currently, there are CF centres that refer PWCF for lung transplant that are geographically quite distant from the MMUH. In these cases, a hybrid model of post-transplant care (combining aspects of models 1 and 2) might be more appropriate. Under this Model, PWCF geographically distant from MMUH may attend their local CF centre, which in addition to being a NCPCF designated CF Centre, will also be resourced to care for PWCF after a lung transplant who present with specific transplant-related complications. The PWCF could attend scheduled appointments at the MMUH for review. The PWCF would attend their CF centre for some of their post-lung transplant follow up, as well as follow up for all non-transplant related complications of CF. All lung transplant PWCF who present to their CF centre with emergent acute transplant complications will have their cases discussed with the transplant physician on call in MMUH to ensure appropriate management.

Under this model, the CF centres will need to have CF physicians with an ongoing interest and expertise in transplant, who will liaise closely with MMUH regarding the management of PWCF post-transplant and, where necessary, transfer cases to MMUH.

This model of care requires close communication between the CF physician and the Transplant team. Transplant-related complications that could not be managed in the local CF centre would result in transfer of the PWCF to the transplant centre.

## **6.2 Recommended Models**

The NCPCF Cystic Fibrosis and Lung Transplantation Subgroup and the NCPCF Working Group have carefully considered the above potential options. The NCPCF Cystic Fibrosis and Lung Transplantation Subgroup and the NCPCF Working Group strongly recommend two Models to address the specific needs of PWCF post-transplant in Ireland. Model 1 will operate for PWCF who live reasonably close to MMUH (in the Leinster area). Model 2 will operate for PWCF who are geographically distant from MMUH.

### **Model 1: Post-transplant care for PWCF solely in MMUH**

The MMUH currently looks after all PWCF who have had a lung transplant. The MMUH liaises closely with all Irish CF centres in the assessment and monitoring of PWCF pre-transplant.

Under this Model, the MMUH will be the specialist centre for the management of all aspects of health of PWCF post-transplant. As such, MMUH will be designated a post-transplant CF centre and will monitor and manage PWCF who are lung transplant recipients. Care for these PWCF will also include the management of extrapulmonary complications that may be partly CF related and pre-existed before transplant such as diabetes, sinusitis, or gastrointestinal problems. To provide this care in both the inpatient and outpatient setting, there are staffing and capital infrastructure resource requirements including:

- i. Consultant Transplant Physician with a special interest in CF
- ii. Transplant/CF Dietician
- iii. Transplant/CF Nurse Specialist
- iv. Transplant/CF Pharmacist
- v. Transplant/CF Physiotherapist
- vi. Transplant/CF Psychologist
- vii. Transplant/CF Social Worker
- viii. Consultant Transplant Microbiologist with a special interest in CF
- ix. Specified sessions for ENT/GI/Diabetes-Endocrine/Renal complications of PWCF post-transplant
- x. Educational Resources including close liaison with CF centres and protected time for CF related CPD/CME.
- xi. Adequate facilities to ensure safe infection control including single room protected CF beds with en-suite bathrooms for inpatient care of PWCF post-transplant.

Additional resource requirements will also include dedicated access to:

- i. Transplant/CF SpR
- ii. Senior scientist in Microbiology
- iii. Administrative Staff including Secretary and Data Clerk
- iv. Diabetes nurse with knowledge of CF and transplant, available to attend Transplant Clinics.

### **Model 2: MMUH and CF Centre both as designated CF post-transplant centres.**

Model 2 is a hybrid model for PWCF at a distance from the transplant centre, dependant on agreement between the referring CF centre and MMUH. In this setting, PWCF will have their care delivered through a hybrid model where the referring CF Centre (now operating as a post-transplant CF centre) manages post-transplant care and CF care, with close collaboration and input from the MMUH transplant team. In rare circumstances and following agreement between MMUH and the referring CF centre, some

PWCF post-transplant who attended the CF centre may have all their post-transplant and CF care at MMUH.

Clear communication between the transplant and the referring CF centre is critical and where appropriate can be enhanced by joint virtual clinics. As such, the NCPCF Designated CF centre will also be designated as a "CF post-transplant centre". To provide this care in both the inpatient and outpatient setting, there are resource requirements for the designated post-transplant CF centre including:

- xii. Consultant CF Physician with a special interest in transplantation
- xiii. CF/Transplant Dietician
- xiv. CF/Transplant Nurse Specialist
- xv. CF/Transplant Pharmacist
- xvi. CF/Transplant Physiotherapist
- xvii. CF/Transplant Psychologist
- xviii. CF/Transplant Social Worker
- xix. Consultant CF Microbiologist with interest in Transplantation
- xx. Additional sessions for ENT/GI/Diabetes-Endocrine/Renal complications of PWCF post-transplant
- xxi. Educational Resources including close liaison with MMUH and protected time for transplant related CPD/CME.
- xxii. Adequate facilities to ensure safe infection control including single room protected CF beds with en-suite bathrooms for inpatient care of PWCF post-transplant.

Additional resource requirements will also include dedicated access to :

- i. CF/Transplant SpR
- ii. Senior scientist in Microbiology dedicated to CF
- iii. Administrative Staff including Secretary and Data Clerk
- iv. Diabetes nurse with knowledge of CF and transplant, available to attend Transplant Clinics.

## 6.3 Special Situations

### 1. Monitoring of Post-transplant Outcomes

Since 2002, the Cystic Fibrosis Registry of Ireland has maintained a database of clinical outcomes on the majority of PWCF in Ireland. This has been a valuable resource for the monitoring of care of PWCF in Ireland and has been an important component of the NCPCF Data and Informatics Strategy. One of the limitations to the CFRI is incomplete data for PWCF post-transplant. It is critical that data from PWCF post-transplant be collected and included in the CFRI, and it is the recommendation of the NCPCF that

data on all PWCF post-transplant is included in the CFRI with serial encounter-level data collected on all outcomes including those relevant to transplant and non-transplant related CF complications. The transplant team will require additional administrative support.

## **2. Solid organ transplantation other than lung transplantation**

Some people with CF may require transplantation of organs other than lungs, especially liver and kidney. Kidney transplantation is seen in PWCF although many of these are after lung transplantation. In Ireland, there are established pathways for the care of PWCF post-transplant of liver/kidney with a shared care model of care between the liver/kidney transplant teams and the CF centres. These pathways currently work well and the NCPCF does not recommend any changes to these pathways at this time. Multi-organ transplantation can happen in rare situations where there is advanced disease in more than one organ requiring transplantation simultaneously. These situations occur rarely and will require in-depth discussion with CF and transplant teams.

## **3. Paediatric Lung Transplantation**

This document is focused on Cystic Fibrosis and Lung Transplantation in adults. It is worth noting that lung transplantation is a rare entity in CF children, especially in the era of CFTR modulation. For Irish PWCF, paediatric transplant surgery takes place in the United Kingdom with follow-up shared between the UK transplant centre and the Paediatric CF centre until the transplant recipient turns sixteen when their post-transplant care transfers to an adult centre. Transition from a paediatric transplant centre to an adult centre often can be a difficult time for the PWCF and their families. An effective transfer helps to improve outcomes for PWCF and excellent communication regarding the post-transplant course and preparing the PWCF and families appropriately is vital.

The NCPCF recommends the development of a Policy document on Cystic Fibrosis and Lung Transplantation in Children to address these issues in the future.

## 7. References

1. Pittman JE, Ferkol TW. The Evolution of Cystic Fibrosis Care. *Chest*. Aug 2015;148(2):533-542. doi:10.1378/chest.14-1997
2. Shah P, Lowery E, Chaparro C, et al. Cystic fibrosis foundation consensus statements for the care of cystic fibrosis lung transplant recipients. *J Heart Lung Transplant*. Jul 2021;40(7):539-556. doi:10.1016/j.healun.2021.04.011
3. Ramos KJ, Smith PJ, McKone EF, et al. Lung transplant referral for individuals with cystic fibrosis: Cystic Fibrosis Foundation consensus guidelines. *J Cyst Fibros*. May 2019;18(3):321-333. doi:10.1016/j.jcf.2019.03.002
4. Hirche TO, Knoop C, Hebestreit H, et al. Practical guidelines: lung transplantation in patients with cystic fibrosis. *Pulmonary medicine*. 2014;2014



All appendices correct as of February 2022, the respective centres/authors should be contacted for the latest version

## Appendix 1: Transplant Information Sheet for PWCF



### LUNG TRANSPLANT



### For people with Cystic Fibrosis in Ireland

This leaflet is a brief introduction to lung transplant and how the process of assessment works for people with Cystic Fibrosis (PWCF). Our hope is that this leaflet will help you understand more about transplant and what's involved and empower you to start discussion with your CF team as you may have questions about it.

The National Heart and Lung Transplant Centre is based in the Mater Misericordiae University Hospital, Dublin. The lung transplant programme began in 2005 and is recognised within Europe as having good success rates and high numbers of transplants per head of population. We perform single and double lung transplants and look after a large number of PWCF post-transplant.

The Mater Hospital recognises that while there are many effective and emerging therapies available to PWCF, unfortunately for some, they may not be sufficient. Lung transplant may be a possible treatment option for PWCF who are no longer responding to standard treatments and/or have declining respiratory ability. Whilst it can be life-saving and life changing, transplant is not a magic cure and not everyone is suitable for a transplant, nor wants one.

*"I'm confused and don't know how to feel about transplant? I'm just thinking about it – I'm not sure if I want one."*

It's ok to feel unsure or uncertain about transplant – it can feel overwhelming and frightening. PWCF have told us that you can never be fully prepared for what transplant entails. However, for many, starting conversations early about lung transplant and asking questions is helpful. Information can empower some people to feel better prepared and have a sense of control or choice.

Sometimes it is when the PWCF finds themselves physically less able, they might consider lung transplant – PWCF who have had a transplant have described this time as *"...when I was not feeling better after IVs and having lots of bad infections close together..."* or *"...when I was spending more and more time in hospital..."*. There's no right time or wrong time to start the conversation with your CF team - this is based on your personal situation, however your annual review may be a good time to explore it more.

You might feel unsure about transplant or if you even want to consider it. This is common and very understandable. Asking questions and discussing transplant does not mean that you need one, but helps you obtain knowledge and understanding early as it may be something you need to consider later on. Sometimes people may feel under pressure from their medical teams or family to make decisions about transplant – this can be challenging and it might be useful to speak with a social worker or psychologist who can support you emotionally.



## GETTING A TRANSPLANT

### How do I get assessed or on a waiting list for a transplant?

If you are considering lung transplant assessment, it's important that you find out more about transplant and think about how it might impact you. If you have any questions, please speak with your CF team. The team in the Mater will provide lots more information at the initial transplant assessment appointment (in-person or virtual).

The following diagram outlines the steps involved in having a transplant, however this journey can be different for everyone. Each person is unique from a medical and psychosocial perspective; therefore how quickly someone copes with and progresses from step to step is different and timeframes vary.

Also, not everyone progresses to the next step, again for a variety of reasons. Some people are not suitable for transplant, some do not wish to have a transplant, and sadly, some do not get a transplant in time as they are too ill. Everyone's journey is unique.

Step 1	Step 2	Step 3	Step 4	Step 5	Step 6
Considering lung transplant	Lung transplant assessment phase	Decision to list on completion of assessment	Waiting for a transplant on the active list	Transplant surgery and post-op recovery	Living with and maintaining health after lung transplant
Timeframe for each step, and progression to the next step, varies based on the individual PWCF.					

#### Step 1: Considering lung transplant

Transplant is a life-long commitment, to yourself and for your family, so it's important to get as much information as you need in order to better understand benefits and challenges. Everyone will have different questions; however some questions to consider may include the following:

- Why am I being referred for assessment?
- How will a transplant affect my life - physically, psychologically and socially?
- What are the potential benefits, risks and challenges of lung transplantation for me?
- What is involved in the assessment process and where does it take place?
- How will my life change if I have a transplant?
- Will I be able to maintain the necessary changes for the rest of my life?
- Who will be my support/care team for transplant?
- What are my hopes/goals for the future and are they compatible with transplant?

Some people may need more time or information than others to consider their options. Please talk to your CF team if you have any questions.

### Step 2: Lung transplant assessment phase

Understanding if someone is suitable for lung transplant is a complex decision. There are many medical and psychosocial criteria that have to be met to be suitable and a range of tests that need to be completed to determine suitability. Many of the medical tests will take place in your CF centre and there are also some appointments with the transplant team in the Mater Hospital.

Compliance with a post-transplant regime including lifestyle changes, medications, diet and exercise management will be discussed early in the assessment as sticking with the programme is crucial for the best possible outcomes.

Medical and psychosocial information will be shared between the CF and transplant team in order to inform the assessment. During this period, certain goals may have to be achieved in order to become more suitable for transplant – with support from your CF team. How long the assessment phase takes, differs from person to person depending on their individual needs.

### Step 3: Decision to list on completion of assessment

Once all the relevant assessment tests and consultations have been completed, a decision about suitability to go on the active waiting list for transplant will be made by the transplant multidisciplinary team in the Mater

### Step 4: Waiting for a transplant on the active waiting list

Places on the active waiting list should only be accepted when people feel ready and fully committed to accepting and living with a transplant and all that it brings. Waiting times vary by person, from hours to years, and there is no way to know how long it will be.

Your CF team will continue to look after you until you have a transplant and it is vital to stay as well as possible while waiting, both physically and psychologically. This helps PWCF recover better after surgery so working with a physiotherapist and dietician is important.

Unfortunately, sometimes people on the active list may become too ill to get a transplant or the risk of transplant is felt to outweigh the potential benefits. In this case people may be suspended or come off the list. This is why we encourage people to start the conversation about transplant earlier rather than later.

### Step 5: Transplant surgery and post-op recovery

When a suitable organ match is found, transplant surgery is done in the Mater Hospital. How long PWCF are in hospital after surgery varies greatly – some people are able to go home after two weeks, but many more need much longer.

During this time, PWCF learn how to live with a transplant and receive a lot of education. Living with a transplant is different than living with CF and changes must be made to routines and previous habits in order to manage the transplant. This will be explained in detail by the transplant team, post-surgery and at the frequent follow up appointments.



### Step 6: Living with and maintaining health after lung transplant

Living with a transplant involves many changes to most people's lives. For example, certain foods can no longer be eaten due to risk of food poisoning and medications must be taken at very specific times each day. All of these changes will be explained during the assessment phase by the transplant team and if considering a transplant, it is important to think about how you and your family will cope with these changes. Lifelong support from and communication between the PWCF, their support team and transplant team is crucial to maintain the transplant.

Everyone's journey is different and it is important not to compare to others. Initially there are frequent appointments with the transplant team, however later on care may be shared between the transplant team and CF centre. Our hope is that transplant will enable PWCF that need them to lead a happy and independent life for as long as possible.

## THINKING ABOUT LUNG TRANSPLANT?

"How will my family cope if I have a transplant? How will I cope financially? Who will support me with practical issues? How will I cope emotionally? Will I feel different?"

The psychological and practical impact of transplant is different for everyone and is discussed during the assessment process.

Some may be concerned about social support, travel, financial costs, accommodation, or time off work, for example. Others may have new or ongoing psychological support needs.

If you need support, please speak with your social worker, psychologist or contact CF Ireland for advice.

### Final points to consider

Transplant has many benefits but also many challenges – it's important to take time and be informed about how it might impact you and your family, before considering it.

Transplant is a treatment and not a cure. Be realistic and honest about how/if you will cope with the many changes it will bring to your life.

Not everyone is suitable for transplant and not everyone wants one - only you can decide what is right for you.

**If you need more information about transplant, please speak to your CF team.**

## PATIENT SUPPORT

Cystic Fibrosis Ireland – [cfireland.ie](http://cfireland.ie) / 01 496 2433 / [info@cfireland.ie](mailto:info@cfireland.ie)

Irish Heart and Lung Transplant Association – [ihlta.com](http://ihlta.com) / 087 221 4753 / [secretary@ihlta.com](mailto:secretary@ihlta.com)

**More information can be found at:** [mater.ie/services/heart-and-lung-transplant](http://mater.ie/services/heart-and-lung-transplant)

## Appendix 2: Referral document to the Transplant Centre



**Mater Misericordiae University Hospital**



### Ireland Adult Lung Transplantation

#### Referral Form

#### Strictly Confidential

This referral has been designed to streamline the referral process for potential lung and heart-lung transplant recipients. As a result potential transplant candidates can be identified more easily and then formally assessed more quickly.

**Referral for lung transplant can only be made by consultant respiratory physician only.**

**Contraindications for lung transplant referral:** Active Smoking, BMI > 35

#### KEY POINTS

1. Please complete all sections - any questions which are not applicable should be marked as N/A
2. When specific results are not available but have been requested please mark as pending.
3. Copies of Imaging that are not available on NIMMS (CT, ultrasound etc) should be sent on CD with this form. <b>Please include local MRN when done in outside hospital</b>
4. Copies of complete reports of investigations can be appended to this referral form but the summary must be completed in the appropriate referral section. Serial PFT reports and 6 minute walk reports are very helpful and should be included when available. <b>Recent ECHO and CT thorax within last 2 years should be included please.</b>

Any questions about this referral form or its use can be addressed by contacting (01) 8032606 or email [lungtransplantreferrals@mater.ie](mailto:lungtransplantreferrals@mater.ie)

Please fax the completed form and documents to: (01 8032985) or Email to [lungtransplantreferrals@mater.ie](mailto:lungtransplantreferrals@mater.ie)

Please mail CDs of imaging studies to:

National Heart and Lung Transplant Centre,  
 Mater Misericordiae University Hospital,  
 Eccles Street,  
 Dublin 7

## TRANSPLANT REFERRAL

PERSONAL DETAILS										
Patient Name										
Age					Date of birth					
Interpreter Required			Yes		No		Language			
Address										
PostCode										
Telephone Number					Mobile Number					
Referring Consultant										
Name										
Address										
Telephone Number					Fax Number				Email Address	
GP Name										
Address (including Postcode)										
Telephone Number					Fax Number				Email Address	
Is patient aware of referral for transplant assessment					Yes		No			
Respiratory History										
Primary Diagnosis										
Secondary Diagnosis										
Other Diagnosis					1.					
					2.					
					3.					
Please give history of when and how diagnosis were made:										
Respiratory Diagnoses made by: Clinical <input type="checkbox"/> CT <input type="checkbox"/> Histology <input type="checkbox"/>										
Current Smoker					Yes		No			
Stopped When					Year Pack History					

### Respiratory Past History / continued

Please describe clinical disease course: Include details on prior treatments for lung disease, approximate start and stop dates, response, rate of decline, life threatening exacerbations and current functional capacity including activities of daily living:

### Past Medical History (Please attach relevant clinical letters from Specialists)

Stroke / TIA	Yes		No	
Heart Disease	Yes		No	
Renal Disease	Yes		No	
Liver Disease	Yes		No	
Diabetes	Yes		No	
Peripheral Vascular Disease	Yes		No	
Malignancy	Yes		No	
G.I. Problems	Yes		No	
Thrombo-embolism	Yes		No	
Osteoporosis	Yes		No	
GERD	Yes		No	
Tube Feeding	Yes		No	
Pregnancies	Yes		No	
Chronic Pain	Yes		No	

Others:

### Past Surgical History

Yes

No

If Yes Provide Details including any previous General Anaesthetics and any issues or known allergies.

Current Medication									
Name			Dose		Frequency				
Known Drug Allergies				Yes		No			
If Yes Provide Details									
Adherences Concerns				Yes		No			
If Yes Provide Details									
Oral Corticosteroids?				Yes		No			
Date Commenced		Max Dose		Current Dose		Dated Stopped			
Response									
Other immunosuppressants received				Yes		No			
If Yes Provide Details below									
Name of Drug			1.						
S/E	Yes		No		Response	Yes		No	
Name of Drug			2.						
S/E	Yes		No		Response	Yes		No	
Name of Drug			3.						
S/E	Yes		No		Response	Yes		No	
Please Provide Details:									

Social History				
Marital Status (Single, Married, Separated/Divorced, Long-term Partner, Widowed)				
Lives Alone	Yes		No	
If Yes Provide Details				
Alcohol	Yes		No	
Previous Alcohol History	Yes		No	
Recreational / Substance Abuse ( Past or Present)	Yes		No	
If Yes to any of the above please give details:				
Relevant Family Medical History:				
Psychological assessment: Current or Previous History of:				
Depression	Yes		No	
Panic Attacks	Yes		No	
Anxiety Neurosis	Yes		No	
Needle Phobia	Yes		No	
Other Psychiatric Conditions.	Yes		No	
If Yes to any of the above please give details:				



<b>Clinical Investigations</b> (Please attach copies if not available on NIMMIS)			
Height Measured		Weight Measured	BMI
			Date Performed
ECG			
Result:			
Echocardiogram in last two years (mandatory investigation for referral)			
Result:			
Chest X-Ray			
Result:			
HRCT Thorax in last two years (mandatory investigation for referral)			
Result:			
Bone Densitometry			
Result:			
Abdominal ultrasound:			
Result:			
Coronary angiography:			
Result:			
Right heart catheter:			
Result:			

**Of Note:-** If results are available on NIMMS please indicate and refer to local MRN

<b>Any Additional Investigations</b>	<b>Yes</b>	<b>No</b>
If yes please provide details (Please attach copies)		

Arterial Blood Gases ( On Room Air)	
pH	
pO <sub>2</sub>	
PCO <sub>2</sub>	
BXS	
HCO <sub>3</sub>	
Sats	
Other:	

Respiratory Function Tests (Please attach serial PFTs)						
	Date:		Date:		Date:	
	Value	% Predicted	Value	% Predicted	Value	% Predicted
FEV <sub>1</sub>						
FVC						
FEV <sub>1</sub> /FVC						
TLC						
FRC						
RV						
TLCO						
KCO						

Laboratory Values (Please attach recent bloods)
Please attach: Haematology, Biochemistry, Microbiology and Virology lab results with recent date.
Any other comments and additional information:

Details of Healthcare Professional completing referral form (Consultant / SPR / Registrar only)	
Title / Name (please print)	
Signature	
Date	

## Appendix 3: MMUH CF MDT Referral Information for Transplant MDT

### MMUH MDT Information Required

MSW Assessment- mostly completed by the patient themselves in advance of meeting the MSW

<b>Name:</b>	<b>DOB:</b>
<b>Address:</b>	<b>MRN:</b>
<b>Marital status:</b> <input type="checkbox"/> Single <input type="checkbox"/> Partnered <input type="checkbox"/> Married <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Widowed	
<b>Respiratory Consultant:</b>	<b>Hospital(s) attending:</b>

#### PERSONAL HEALTH HISTORY

<b>List any medical problems you have</b>			
Do you have a GP?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Does anyone else in your family suffer with a similar respiratory illness?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Do you use portable oxygen?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
When did you start using portable oxygen?			
How much oxygen do you use?			
Does someone help you with your medications?	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you ever forget to take your medications?	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you use a blister pack for your medications? (prepared by your community pharmacist)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
How do you pay for medications?	<input type="checkbox"/> Medical card	<input type="checkbox"/> Drugs payment scheme	<input type="checkbox"/> LTI <input type="checkbox"/> Other
Does someone usually attend medical appointments with you?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Who?			

<b>List your prescribed drugs</b>		
Name the Drug	Why do you take this drug?	Frequency Taken

#### HEALTH HABITS

MRN:

Page 1

## MMUH MDT Information Required

<b>Pulmonary Rehab</b>	<input type="checkbox"/> Have never attended/have not been referred <input type="checkbox"/> Referred but waiting to attend <input type="checkbox"/> Have completed a course - please state where: <input type="checkbox"/> Started but too unwell to complete - please state where: <input type="checkbox"/> I do an alternative exercise program e.g. COPD group or private physiotherapy		
<b>Exercise</b>	<input type="checkbox"/> Sedentary (No exercise) <input type="checkbox"/> Mild exercise (e.g. climb stairs, walking, golf) <input type="checkbox"/> Occasional vigorous exercise (e.g. work or recreation, less than 4x/week for 30 min.) <input type="checkbox"/> Regular vigorous exercise (e.g. work or recreation 4x/week for 30 minutes)		
<b>Equipment</b>	Do you have an exercise bike or equipment at home?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<b>Diet</b>	Have you been advised to lose weight?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Have you been advised to increase weight?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Do you know what your ideal weight is for transplant?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Do you attend a dietician?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Have you a special diet?		
<b>Alcohol</b>	Do you drink alcohol?	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Yes <input type="checkbox"/> No
	If yes, what kind?		
	How many drinks per week on average?		
	Are you or your family members concerned about the amount you drink?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Have you considered stopping?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Have you ever experienced blackouts?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Are you prone to "binge" drinking?	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Do you drive after drinking?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Do you think you would have difficulty stopping drinking alcohol?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Have you been advised to stop drinking alcohol for transplant?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<b>Tobacco</b>	Do you use tobacco?	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Yes <input type="checkbox"/> No
	<input type="checkbox"/> Cigarettes – pks/day <input type="checkbox"/> E-cigarette <input type="checkbox"/> Pipe <input type="checkbox"/> Cigars <input type="checkbox"/> # of years <input type="checkbox"/> Or year quit		
<b>Drugs</b>	Do you currently, or in the past, used recreational or street drugs?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Have you ever given yourself street drugs with a needle?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

### CF CENTRE – PLEASE COMPLETE IF YOU HAVE CF

Which CF Centre do you attend?			
Do you see the CF social worker in your CF centre?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Do you see the CF psychologist in your CF centre?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	
Are you aware of the supports/grants available from CF Ireland?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	

## MMUH MDT Information Required

HOME ENVIRONMENT				
Is your home....?	<input type="checkbox"/> Rented	<input type="checkbox"/> Council	<input type="checkbox"/> Privately owned	<input type="checkbox"/> Other
Do you have stairs in your home?				<input type="checkbox"/> Yes <input type="checkbox"/> No
Do you have a stair lift?				<input type="checkbox"/> Yes <input type="checkbox"/> No
Do you have any damp or mould in your home?				<input type="checkbox"/> Yes <input type="checkbox"/> No
Do you have any pets inside your home?				<input type="checkbox"/> Yes <input type="checkbox"/> No
Do you have any pets outside the home?				<input type="checkbox"/> Yes <input type="checkbox"/> No
Do you have a toilet downstairs?				<input type="checkbox"/> Yes <input type="checkbox"/> No
Do you have any questions about your home following transplant?				<input type="checkbox"/> Yes <input type="checkbox"/> No

MENTAL HEALTH		
Have you or do you suffer with anxiety or depression?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Have you ever had a panic attack?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you have problems with eating or your appetite?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you cry frequently?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Have you ever attempted suicide?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Have you ever self-harmed (e.g. cutting)?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you have trouble sleeping?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Have you ever been treated by a psychiatrist?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Have you ever or are you currently attending a counselor, social worker or psychologist?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Are you prescribed medications to help your mood/to cope better/relax?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Have you ever had treatment for alcohol, drug or any other addiction?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you attend a support group?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

FUNCTION		
Are you able to dress/groom yourself?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you need assistance to have a shower or wash your hair?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you live alone?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you have frequent falls?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you use a mobility aid?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you have any difficulty remembering things?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you have any difficulties with writing?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you have any difficulties with reading?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you have any difficulties with numbers?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you wear glasses or have any difficulties with your sight?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you wear hearing aids or have any difficulties with your hearing?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Have you have home help or private carers to assist you?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Are you linked in with your local district health nurse or public health nurse?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Are you linked in with any other community services e.g. occupational therapist or physiotherapist?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

## MMUH MDT Information Required

### OCCUPATIONAL BACKGROUND

Educational level	<input type="checkbox"/> Primary school	<input type="checkbox"/> Secondary school	<input type="checkbox"/> 3 <sup>rd</sup> Level	<input type="checkbox"/> Other
Are you in paid employment?				<input type="checkbox"/> Yes <input type="checkbox"/> No
What is your current or most recent job?				<input type="checkbox"/> Yes <input type="checkbox"/> No
Do you hope to return to work after transplant?				<input type="checkbox"/> Yes <input type="checkbox"/> No
Have you thought about how you will cope financially if you are unable to work for a period of time?				<input type="checkbox"/> Yes <input type="checkbox"/> No
Do you need information or advice about financial issues?				<input type="checkbox"/> Yes <input type="checkbox"/> No

### KNOWLEDGE ABOUT TRANSPLANT

Have you received the transplant information booklet?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Have you read the transplant information booklet?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Have ALL members of your care team read the transplant information booklet?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do you have any concerns about transplant?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Do your family/carers have any concerns about transplant?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
What are your hopes for the future, should you receive a transplant (e.g. work/travel/family/education etc.)?		

### ANY QUESTIONS, COMMENTS OR CONCERNS?

Have you any further questions, comments or concerns?

Thank you for filling out this questionnaire - please give it to the medical social worker or CF nurse on completion.

### FOR COMPLETION BY MEDICAL SOCIAL WORKER – DATE:

Initial MSW review completed?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Family meeting completed?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Further MSW review indicated?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Care plan completed?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Psychiatry review completed?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
GOALS:		
RECOMMENDATION:		

MRN:

Page 4



## MMUH MDT Information Required

<b>Patient Name:</b>		<b>Date of Birth:</b>		<b>Date:</b>	
<b>Medical History</b> (of relevance – if gastrostomy tube in-situ document type, size and when last changed):					
<b>Social History:</b>					
<b>1. Medical tests &amp; procedures</b> (of relevance)					
<b>2. Biochemistry</b>	Vitamin A:	RBP:	Zinc:	CRP:	Vitamin D: Vitamin E:
	Vitamin E/ (Chol + TG):		Vit K:	HbA1c:	OGTT (if relevant):
<b>3. Medications</b>	PERT type and iu:fat ratio: Fat soluble vitamin regimen: Laxative regimen: Insulin: Others of relevance (e.g. PPIs, motility agents, appetite stimulants) :				
<b>4. Nutrition focused physical findings</b>	Appetite: Nausea: Vomit: Reflux symptoms: Bowels (include history of DIOS): Nutrition Focused Physical Exam: Handgrip strength:				
<b>5. Anthropometric measurements &amp; Comparative Standards</b>	Height: Current weight: Dry weight (if relevant): BMI: Weight History: Weight target (if relevant): <u>Nutritional Requirements</u> Calories: Protein:				
<b>6. Nutritional Intake</b>	Dietary pattern: Oral nutritional support regimen (including PERT dosing): Enteral nutrition regimen (including PERT dosing): Adherence to nutritional recommendations:				
<b>7. Nutrition Diagnosis &amp; Nutritional Issues</b>					
<b>8. Nutrition Intervention</b>					
<b>Dietitian Name:</b>		<b>CORU Number:</b>		<b>Date:</b>	

## MMUH MDT Information Required

### PHYSIOTHERAPY REFERRAL LETTER

<b>Name:</b>		<input type="checkbox"/> M <input type="checkbox"/> F
<b>Address:</b>		
<b>Medical card:</b> Yes <input type="checkbox"/> No <input type="checkbox"/>	Medical card no.	
<b>Referring physiotherapist:</b>	<b>Email:</b>	

#### PRESENTING CONDITION AND HISTORY

**Presenting complaint**

**History of presenting complaint**

**Past medical history**

**Medications (include nebulisers)**

#### Oxygen

**Does patient require oxygen?** Yes ☐ No ☐

**Oxygen company**

Air Liquide ☐ BOC ☐

**Method of delivery**

Nasal cannula ☐ High flow nasal cannula ☐ Facemask ☐ Venturi ☐ Oxymask ☐

**Oxygen at rest**

Concentrator ☐ Portable oxygen cylinder ☐ SeQual ☐ Inogen ☐ Liquid O2 ☐ Airvo ☐

Direct/continuous flow ☐ Pulsed ☐

Oxygen Flow Rate: \_\_\_\_\_ lpm or setting \_\_\_\_\_

Hours per day: \_\_\_\_\_ hours OR PRN ☐

**Oxygen on mobilizing**

Concentrator ☐ Portable oxygen cylinder ☐ SeQual ☐ Inogen ☐ Liquid O2 ☐ Airvo ☐

Direct/continuous flow ☐ Pulsed ☐

Oxygen Flow Rate: \_\_\_\_\_ lpm or setting \_\_\_\_\_

Hours per day: \_\_\_\_\_ hours OR PRN ☐

How is the oxygen transported: Oxykart ☐ Backpack ☐ Other \_\_\_\_\_

Additional details e.g. CPAP at night

MRN:

Page 6



## MMUH MDT Information Required

Maintaining target spO2 parameters on current oxygen at rest	Yes <input type="checkbox"/> No <input type="checkbox"/>
Maintaining target spO2 parameters on current oxygen on mobilizing	Yes <input type="checkbox"/> No <input type="checkbox"/>
<b>Social History</b>	
Lives with	<input type="checkbox"/> alone <input type="checkbox"/> with family <input type="checkbox"/> other
Further details	
<hr/>	
Formal supports	<input type="checkbox"/> None <input type="checkbox"/> Meals on Wheels <input type="checkbox"/> PHN <input type="checkbox"/> Home Help. If yes, what days/how long/what do they do
<hr/>	
<b>Home environment</b>	
Accommodation:	<input type="checkbox"/> Storey house <input type="checkbox"/> Bungalow <input type="checkbox"/> Floor Apartment
Internal steps	<input type="checkbox"/> Yes <input type="checkbox"/> No
Details	
External steps	<input type="checkbox"/> Yes <input type="checkbox"/> No
Details	
Bedroom	<input type="checkbox"/> Upstairs <input type="checkbox"/> Downstairs
Bathroom	<input type="checkbox"/> Upstairs <input type="checkbox"/> Downstairs
Toilet	<input type="checkbox"/> Upstairs <input type="checkbox"/> Downstairs
<b>Other</b>	
Occupation	
Hobbies	
<b>Baseline physical activity levels</b>	
<b>Mobility status:</b>	
Indoor mobility	
Outdoor mobility	
<b>6MWT</b>	
Date ___ / ___ / ___	
Completed 6 minutes <input type="checkbox"/> Yes <input type="checkbox"/> No	
Distance	
Spo2 pre-test	Heart rate pre-test
Spo2 post-test	Heart rate post-test
Any other symptoms at end of test	
<b>Chest clearance</b>	
Daily routine Yes <input type="checkbox"/> No <input type="checkbox"/>	
If yes, what do you do (eg. mobilise, bike, nebulisers, ACBT, acapella, at what time of day)	
<hr/>	

## MMUH MDT Information Required

### Pharmacy Information required for CF Transplant Handover

1. Current list of medications and doses. This needs to be updated when changes are made. Include vitamins, herbal and alternative medications and contraception including depot/implant agents.
2. Allergies- particularly allergies to antimicrobials, needs to be explicit about the nature of the allergy and anything which has been successfully used to aid tolerability of the agents e.g. slower titration, antihistamine cover, desensitisation.
3. Current "best" antimicrobial regimen including doses, needs to be updated if it changes
4. Assessment of adherence to medications. Following transplant, adherence to medications needs to be 100%, in particular to immunosuppression, nebs and GI medications.
5. If the candidate has osteoporosis/osteopenia please state date that treatment was started and monitor effect.

## Appendix 4: MMUH Heart / Lung Transplant Assessment Checklist



### Mater Misericordiae University Hospital Heart / Lung Transplant Assessment Checklist



Patient's Name:

MRN:

Laboratory Testing	Completed (please insert ✓)	Date & Sign
FBC		
CRP		
ESR		
Coagulation Screen		
Fibrinogen		
Urate		
Renal, Liver & Bone Profile		
Urinary Creatinine Clearance (24 hour collection)		
Iron Profile		
Thyroid Function		
Glucose		
HbA1C		
Cholesterol		
Serum Protein Electrophoresis, Serum free light chains		
Serum Immunoglobulins		
Cardiac Biomarkers-Heart Only (troponin, ck, bnp, ldl, hdl)		
Blood Group		
Myositis Panel- Lung Only (ENA Screen, ANCA, ANA, RF, AntiDsDNA, C3, C4 (ILD lung patients only))		
Microbiology Testing	Completed (please insert ✓)	Date & Sign
Mantoux Quantiferon		
CRE		
VRE		
MRSA		
Covid vaccine – Type 1,2 & boosters and Date		
Virology Testing	Completed (please insert ✓)	Date & Sign
To be sent to NVRL & Consent Required for HIV		
HIV 1 +2 Ag/Ab serum		
HTLV 1 & 2		
Hepatitis A IgG Antibody		
Hepatitis A IgM Antibody		
HBV Surface Antigen (HBsAg)		
Anti Hb Core Total		
Hepatitis C Antibody		
Hepatitis C Antigen		
T.Pallidum IgG		

HLT-F-0053, Rev 4

Transplant Coordinators Contact Details:

Tel No: 8032984 / 2986 / 4274 / 5447

Email: transplantco@mater.ie

Page 1



**Mater Misericordiae University Hospital**  
**Heart / Lung Transplant Assessment Checklist**

**Patient's Name:**

**MRN:**

<b>Virology Testing</b> <i>To be sent to NVRL &amp; Consent Required for HIV</i>	<b>Completed</b> <i>(please insert √)</i>	<b>Date &amp; Sign</b>
Herpes Simplex IgG		
CMV IgG		
EBV IgG		
Varicella Zoster IgG		
Toxoplasma IgG		
<b>Sputum Testing- Lung only</b>	<b>Completed</b> <i>(please insert √)</i>	<b>Date &amp; Sign</b>
Culture & Sensitivity		
TB Testing		
<b>Cytotoxic Antibodies &amp; Tissue Typing x 2 Sets</b> <i>(Send to H&amp;I Laboratory, Beaumont)</i>	<b>Completed</b> <i>(please insert √)</i>	<b>Date &amp; Sign</b>
List HLA antibodies		
PGEN 4 <sup>+</sup>		
PGEN 10 <sup>+</sup>		
Auto cross matching (lungs only) <i>(Please send samples on Mon, Tues, Wed only)</i>		
<b>Cardiology Testing</b>	<b>Completed</b> <i>(please insert √)</i>	<b>Date &amp; Sign</b>
ECG		
Echocardiogram		
RHC		
Coronary Angiography		
<b>Pulmonary Investigations</b>	<b>Completed</b> <i>(please insert √)</i>	<b>Date &amp; Sign</b>
PFTs including indicating TLC on helium or body box		
Arterial Blood Gases (Lung only)		
<b>Radiology Testing</b>	<b>Completed</b> <i>(please insert √)</i>	<b>Date &amp; Sign</b>
Chest X-Ray		
CT Thorax		
V/Q scan (lung only)		
CT of Sinuses (CF/bronchiectasis)		
Dexa Scan		
<b>G.I. Testing</b>	<b>Completed</b> <i>(please insert √)</i>	<b>Date &amp; Sign</b>
Colonoscopy <i>(only CF Patients &gt; 40 years, all other patients &gt; 50 years)</i>		
pH Manometry <i>if patient has symptoms of GORD</i>		
FOB x 3 <i>(if patient &gt; 45 years or anaemic)</i>		



**Mater Misericordiae University Hospital**  
**Heart / Lung Transplant Assessment Checklist**



**Patient's Name:**

**MRN:**

Vascular Studies	Completed (please insert √)	Date & Sign
Carotid Dopplers +/- ABIs <i>(only if &gt; 50 years of age, Risk Factors for CVD/PVD) ISHLT guidelines;</i>		
Femoral Artery Ultrasound <i>(If ECLS is anticipated)</i>		
Gender Specific Screening	Completed (please insert √)	Date & Sign
Mammogram and clinical breast examination (> 40 years of age)		
Pelvic Ultrasound <i>(females &gt; 50 years &amp; gynae symptoms)</i>		
Pap Smear <i>(intervals between testing per updated guidelines for &gt; 18 years of age)</i>		
Prostate Specific Antigen <i>(&gt; 50 years at listing &amp; annually while on list)</i>		
Physiotherapy Testing	Completed (please insert √)	Date & Sign
6 Min Walking Test <i>(include actual and predicted walk distance and desaturation and on how much oxygen)</i>		
Frailty Indices Testing	Completed (please insert √)	Date & Sign
Hand grip strength		
Fried Frailty Phenotype		
Short Physician Performance Battery		
Dental Investigations	Completed (please insert √)	Date & Sign
Orthopantomogram		
Dental Review		
Consults Required	Completed (please insert √)	Date & Sign
Psychiatry Review		
Social Work Review		
Dietician Review		
Transplant Coordinator Review / Education		
Post Heart Transplant CNS Consult / Education		
Cardiothoracic Surgeon Review 1		
Cardiothoracic Surgeon Review 2		



## Appendix 5: HSE recommendation on Vaccination in the Immunocompromised

Vaccine	Pre-SOT	Post-SOT, if immunisation not completed pre transplant	1 <sup>st</sup> Date (vaccine)	2 <sup>nd</sup> Date (vaccine)	3 <sup>rd</sup> Date (vaccine)	4 <sup>th</sup> Date (vaccine)
<b>Hep A</b> (if seronegative)	Yes	Yes				
<b>Hep B</b> (if HBsAG negative & Anti_HBs<10miu/L)	Yes (i.e., HBVAXPRO40® or Fendrix®)	Yes				
<b>Hib</b> (consider for lung transplant)	Yes	Yes				
<b>HPV</b>	Yes	Yes				
<b>Inactivated Influenza</b> (annual)	Yes	Yes				
<b>MenACWY</b> (if at increased risk)	Yes	Yes				



<b>MenB</b> (if at increased risk)	Yes	Yes				
<b>MMR</b> (unless laboratory evidence of immunity to each antigen or documented prior vaccination)	Yes (complete at least 1 month prior to transplant)	No				
<b>PCV13</b>	Yes	Yes				
<b>PPV23</b> (at least 2 months post PCV)	Yes	Yes				
<b>Tdap</b> <b>Or</b> <b>Tdap/IPV</b>	Yes, if not received within 10 years. Use if not fully immunised with IPV	Yes, if not received with 10 years. Use if not fully immunised with IPV				
<b>Varicella</b> (unless seropositive or documented prior vaccination)	Yes (complete at least 1 month prior to transplant)	No				
<b>Zoster</b> (shingrix® is preferred)	Yes if > 50 yrs	No				
<b>COVID-19</b>	Yes	Yes				

All require annual inactivated influenza vaccine from 6 months of age (2 doses 4 weeks apart in the first season of receipt)



