Post-Lung Transplant Care Checklist

A Tool for CF and Transplant Providers

Patient :	**DOB :**
Transplant Program :	**CF Program :**

As adult lung transplant recipients with cystic fibrosis experience a median survival of 10 years, the extra-pulmonary manifestations of CF are important to manage. These manifestations include nutritional considerations, GI concerns, sinus disease, CF-related diabetes, bone health, mental health, and an increased risk of cancer related to, but not limited to, the use of immunosuppressive therapy. These warrant specialized attention, as detailed in the consensus statements for the care of cystic fibrosis lung transplant recipients.

To address models of post-transplant care, the CF Foundation convened an international committee to address how to best integrate and manage the transplant and non-pulmonary elements of CF care following transplantation. The most appropriate model for people with CF will depend on many factors involving resources, knowledge, and experience of the transplant center, the CF center, and the individual needs and circumstances of the person with CF. The care model should be determined through shared decision-making between the transplant recipient, family, and CF and transplant care teams. Clear communication and delineation of responsibilities are essential to optimize quality of life and survival after a lung transplant.

The purpose of this tool and checklist are to outline the elements of high-quality care for the CF lung transplant recipient.

CARE OVERVIEW

Applicable to All Care Teams

CANCER SCREENING

Due to the immunosuppressive nature of drugs needed post-transplant, this section highlights some cancers seen at increased risk in transplant recipients, however, it is not all-inclusive. Other cancer screening, such as for prostate cancer, should be completed per current screening guidelines for the general population

- ☐ Begin colorectal screening within two years of transplant for individuals ≥30 years old, except if a negative colonoscopy has been obtained within the past five years
- ☐ Rescreen for colorectal cancer every five years
  - Perform surveillance colonoscopy in three years if the original colonoscopy resulted in adenomatous polyps, unless a shorter interval is indicated by individual findings
  - Base subsequent intervals on the most recent endoscopic examination
- ☐ Annual skin cancer screening, with more frequent screening as recommended by dermatologist
- ☐ Screen for breast cancer every two years for women aged 40-74
- ☐ Screen for cervical cancer via cervical cytology every six months for the first year after transplant if sexually active or ≥21
  - Begin cervical cancer screening early, in comparison to healthy women
  - Screen every one to three years depending on prior screening results
- ☐ Discuss screening for post-transplant lymphoproliferative disorder (PTLD) with Epstein-Barr virus (EBV) PCR assays, particularly if transplant recipient is mismatched for EBV

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DIABETES

- [ ] Unknown diabetes: Screen at three to six months post-transplant for cystic fibrosis related diabetes (CFRD)
    - Continue annual screening using oral glucose test or hemoglobin A1C
- [ ] Known diabetes: optimize glucose control through longitudinal care with endocrinologist with experience in CF or transplant-related diabetes

INFECTION PREVENTION

- [ ] Operationalize infection prevention policies as indicated by the CF Foundation's Infection and Prevention Guidelines in conjunction with institutional guidelines

MEDICATION DOSING

- [ ] Choose and dose medications appropriate for renal function; when possible, use therapeutic drug monitoring
    - Consider use of cystatin C and 24-hour urine to guide dose of nephrotoxic drugs on recipients with low muscle mass; creatinine may be poor indicator of glomerular filtration rate
    - Tobramycin may accumulate when given by inhalation and require dose reduction to avoid worsening renal function
    - Use IV contrast judiciously and only when necessary
- [ ] Transplant Team to manage dosing of immunosuppression

MENTAL HEALTH SCREENING

- [ ] Perform mental health screening for depression and anxiety for transplant recipients ≥12 with the GAD-7 and PHQ-9 annually and at disease milestones (significant decline in clinical course)

SHARED CARE

- [ ] Follow-up with a multidisciplinary CF care team for extrapulmonary care 6-12 months post-transplant and at least annually
- [ ] Address goals of care as appropriate, including palliative care as indicated

VACCINATION

- [ ] Review vaccination status and establish a vaccination plan in alignment with the American Society of Transplantation and the CDC Advisory Committee on Immunization Practices

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VITAMINS

- [ ] Discontinue combination vitamins A, D, E, and K supplements post-transplant
- [ ] Continue vitamin D supplementation
- [ ] Measure fat-soluble vitamin levels to guide supplementation by three months post-transplant and annually

TRANSPLANT CENTER FOCUS POINTS

- [ ] Manage and monitor all aspects of immunosuppression and lung function
- [ ] Manage infection prophylaxis and monitor for opportunistic infections

CYSTIC FIBROSIS CARE CENTER FOCUS POINTS

BONE HEALTH

- [ ] Assess bone density with dual energy X-ray absorptiometry (DEXA) 6 to 12 months post-transplant and at least every 1 to 5 years depending on DEXA results

SINUS DISEASE

- [ ] Assess for symptoms of chronic rhinosinusitis (CRS), including home spirometry and PFTs, and refer to otolaryngologist with experience in CF sinusitis when appropriate

LIVER DISEASE

- [ ] Screen for CF liver disease with at least annual liver function testing
    - Pursue non-invasive imaging and referral to hepatologist for recipients with liver dysfunction

NUTRITION AND METABOLISM

- [ ] Consult annually with a dietitian with CF expertise to obtain individualized nutritional therapy to obtain an optimal BMI
- [ ] Screen annually for hyperlipidemia
    - Address abnormalities

ENGAGEMENT OF CONSULTANTS

New non-pulmonary specialist referrals post-transplant are to be coordinated between the transplant and CF center to ensure delivery of care promotes good communication between the non-pulmonary specialist and the transplant and CF centers.

Many non-pulmonary complications after transplant require subspecialty care beyond the transplant and CF teams. For CF individuals followed by non-pulmonary specialists at their CF center before transplant, continued follow-up after transplant, if needed, has advantages unless specific transplant-related complication expertise is only available at the transplant center.

DERMATOLOGIST

- [ ] Screen for skin cancer annually or more frequently as recommended by a dermatologist

ENDOCRINOLOGIST

- [ ] Consult with endocrinologist with transplant associated diabetes mellitus expertise when necessary
- [ ] Consider referring recipients with bone disease to a bone health specialist

GASTROENTEROLOGIST

- [ ] Consult with gastroenterologist or hepatologist for patients with significant reflux, gastroparesis, or liver dysfunction
- [ ] Begin colorectal screening within two years of transplant for individuals ≥30 years old
    - Except if a negative colonoscopy has been obtained within the past five years

- [ ] Rescreen for colorectal cancer every five years
    - A colonoscopy resulting in adenomatous polyps must have a surveillance colonoscopy in three years, unless a shorter interval is indicated by individual findings
    - Base subsequent intervals on the most recent endoscopic examination

NEPHROLOGIST

- [ ] Consult with nephrologist, ideally with experience in transplant, when eGFR declines to <60
    - Discuss renal transplant referral with stage 4 CKD

OTOLARYNGOLOGIST

- [ ] Consult with otolaryngologist experienced in CF for recipients with moderate to severe CRS for consideration of optimal topical therapies and endoscopic sinus surgery
- [ ] Consult with otolaryngologist with CF expertise for recipients who have had multiple bacterial allograft infections, regardless of their CRS symptoms

WOMEN'S HEALTH

- [ ] Ensure adequate birth control and avoid pregnancy in the first two years after transplant
- [ ] Use shared decision making with transplant providers and maternal fetal medicine to discuss if, and when, it is safe to conceive and make any necessary medication adjustments for female transplant recipients interested in pursuing pregnancy

TO LEARN MORE

This Checklist Refers to the Following Publications[1]

Cystic Fibrosis Foundation consensus statements for the care of cystic fibrosis lung transplant recipients

Initial skin cancer screening for solid organ transplant recipients in the United States: Delphi method development of expert consensus guidelines

Clinical Care Guidelines for Cystic Fibrosis–Related Diabetes: A position statement of the American Diabetes Association and a clinical practice guideline of the Cystic Fibrosis Foundation, endorsed by the Pediatric Endocrine Society

Models of Palliative Care Delivery for Individuals with Cystic Fibrosis: Cystic Fibrosis Foundation Evidence-Informed Consensus Guidelines

Cystic fibrosis colorectal cancer screening consensus recommendations

Vaccination of solid organ transplant candidates and recipients: Guidelines from the American Society of Transplantation Infectious Diseases Community of Practice

Human papillomavirus-related cancer risk for solid organ transplant recipients during adult life and early prevention strategies childhood and adolescence

US Preventive Services Task Force, Breast Cancer: Screening

International Committee on Mental Health in Cystic Fibrosis: Cystic Fibrosis Foundation and European Cystic Fibrosis Society consensus statements for screening and treating depression and anxiety

Guide to Bone Health and Disease in Cystic Fibrosis

Position paper: Models of post-transplant care for individuals with cystic fibrosis

Cystic fibrosis screening, evaluation and management of hepatobiliary disease consensus recommendations

Screening and Management of PTLD

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1. Publications selected by subject matter experts