

# Ontario's Referral and Listing Criteria for Paediatric Heart Transplantation

Version 1.0

Trillium Gift of Life Network



# Paediatric Heart Transplantation Referral & Listing Criteria

Heart transplantation candidates under the age of 18 years old are considered paediatric patients.

### PATIENT REFERRAL CRITERIA:

The patient referral criteria are guidelines which a Health Care Provider would utilize to refer a patient to a transplant center for assessment. The criteria identified below are the conditions for which a paediatric patient should be referred for heart transplant assessment.

- 1) Advanced Heart Failure: Referral for heart transplantation should be considered for patients with advanced heart failure failing optimal medical and surgical (if appropriate) therapy.
- 2) Anticipated Survival: Referral for heart transplantation should be considered for patients with poor anticipated survival without a transplant. These may be patients with excessive disability, unacceptably poor quality of life, or long-term morbidity in the setting of failing myocardial function, complex congenital heart disease, or after failed surgical palliation of congenital heart disease.
- 3) Arrhythmias: Referral for heart transplantation should be considered for patients who have malignant, refractory, life-threatening arrhythmias despite optimal medication, surgical, and device management.
- **4) Cardiomyopathy**: Referral for heart transplantation should be considered for patients with cardiomyopathy in advanced stages of the disease process despite medical management (e.g. dilated, hypertrophic, or restrictive cardiomyopathy).
- 5) Congenital Heart Disease: Referral for heart transplantation should be considered for patients with congenital heart diseases that result in progressive cyanosis, advanced heart failure (see above), or other related non-cardiac diagnoses (e.g. protein-losing enteropathy or plastic bronchitis) not amenable to interventional therapy, surgical repair or palliation.
- 6) Quality of Life: Referral for heart transplantation should be considered for patients who, if without a transplant, would be excessively disabled, experience an unacceptably poor quality of life, or have long-term morbidity in the setting of failing myocardial function, complex congenital heart disease, or after failed surgical palliation of congenital heart disease.

Early referral is essential, allowing for pre-transplant problems to be addressed and optimized while the disease is relatively well-compensated.

### PATIENT LISTING INDICATIONS:

Each patient is assessed individually on their suitability for heart transplantation by the transplant program. The criteria identified below are the conditions for which a paediatric patient may be eligible to be waitlisted for heart transplantation in Ontario.

- 1) Advanced Functional Class: Patients who have end-stage myocardial failure despite maximal medical therapy may be considered for transplant listing. Patients who are diagnosed with advanced functional class and/or heart failure stage (i.e. Class III, IV or Stage D) may also be considered for transplant listing.
- 2) Arrhythmias: Patients who have malignant, refractory, life-threatening arrhythmias despite optimal medication, surgical, and device management may be considered for transplant listing.
- 3) Cardiomyopathy: Patients with cardiomyopathy at advanced stages of the disease (e.g. dilated, hypertrophic, or restrictive cardiomyopathy) may be considered for transplant listing.
- 4) Cardiac Tumour: Patients who have unresectable cardiac tumours causing obstruction or ventricular dysfunction (systolic or diastolic) or refractory arrhythmias may be considered for transplant listing.
- 5) Congenital Heart Disease: Patients with complex congenital heart disease (CHD) and no acceptable options for surgical palliation may be considered for transplant listing. Patients who have progressive cyanosis in the presence of complex CHD and no amenability to surgical repair or palliation may also be considered for transplant listing.
- 6) Lack of Alternative Medical Options: Patients who fail to respond to maximal medical therapy or the absence of alternative/conventional surgical options are eligible to be waitlisted for heart transplantation in Ontario.
- 7) Contraindications: The absence of contraindication(s) for transplant is required to be eligible to be waitlisted for heart transplantation.
- **8) Rehabilitation**: The potential to undergo rehabilitation after transplant is required to be eligible to be waitlisted for heart transplantation.

### ABSOLUTE LISTING CONTRAINDICATIONS:

The following are conditions relating to the heart transplant candidate that constitute absolute contraindications to heart transplantation. As such, they prevent a transplant from being done until the condition is resolved.

1) Consent: Patients who do not want a transplant should not be listed for heart transplantation. Patients who are unable to give informed consent and do not have a substitute decision maker available, resulting in an inadequate or unsafe care plan post-transplant, are not candidates for heart transplantation.

## RELATIVE LISTING CONTRAINDICATIONS:

The following are conditions relating to the heart transplant candidate that constitute relative contraindications to heart transplantation. While each patient is evaluated on an individual basis, the presence of one or more of the following may preclude a candidate from being listed on the heart transplantation wait list.

- 1) **Diabetes:** Patients with insulin-dependent diabetes with evidenced end-organ damage may not be eligible for heart transplantation.
- 2) Other Diagnoses: Patients with chromosomal, neurologic, neuromuscular, or syndromic diagnoses may not be eligible for heart transplantation.
- 3) Anatomic: Patients with pulmonary vein atresia or progressive stenosis, severe hypoplasia of the branch pulmonary arteries, and/or severe hypoplasia of the thoracic aorta may not be eligible for heart transplantation.
- 4) **Immunization:** Patients who are not completely immunized may not be eligible for heart transplantation.
- 5) **Infections:** Patients with active infection (whether of viral, bacterial or fungal origin) without acceptable clinical response to treatment may not be eligible for heart transplantation.
- **6) Malignancy**: Depending on prognosis, patients with a history of malignancy may not be eligible for heart transplantation.
- 7) **Mechanical Circulatory Support:** Patients on mechanical circulatory support (MSC) or temporary ventricular assist device with identified risk factors that preclude reasonable survival to hospital discharge may not be candidates for heart transplantation. These factors may include the following: complex CHD at any stage of palliation; moderate to severe renal insufficiency; age <1 year; instability on mechanical support; fungal infection; or, ventilator dependency for oxygenation and/or requiring high pressures.
- **8) Multisystem Organ Failure:** Patients with progressive, refractory, or irreversible multisystem organ failure may not be eligible for heart transplantation.
- **9) Pulmonary Hypertension:** Depending on patient age, underlying disease/heart diagnosis, and response to aggressive testing in cardiac catheterization, patients with pulmonary hypertension may not be eligible for heart transplantation.
- **10) Systemic Disease:** Patients with progressive systemic disease (ex. genetic, metabolic, idiopathic, mitochondrial, syndromic, etc.) that foreseeably limit post-transplant survival or may result in early mortality may not be candidates for heart transplantation.
- 11) Psychosocial Considerations: Patients and their family members must undergo a complete psychosocial evaluation prior to listing for transplant. Patients who are in psychosocial and/or social circumstances that jeopardize post-transplant care and survival in the opinion of the interdisciplinary team following appropriate assessment and intervention may not be candidates for heart transplantation.
- **12) Social Support:** Patients for whom social supports are deemed insufficient to achieve compliant care in the outpatient setting.

# **GENERAL CONSIDERATIONS:**

In addition to the above criteria, the following should be considered when assessing candidates for heart transplantation.

1) **Human Leukocyte Antigen (HLA) Sensitization**: Levels of Human Leukocyte Antigen (HLA) antibodies are considered when assessing candidates for heart transplantation.

# **Version Control:**

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