

THALASSEMIA TREATMENT GUIDELINES

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Network of Rare Blood Disorders Organization
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Thalassemia Foundation of Canada

Anemia Institute for Research & Education

Thalassemia Clinicians and Nurses

Patients/Families

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Goals and Scope

Improving overall health and quality of life for thalassemia patients

Essential components of multidisciplinary team approach

Current evidence-based best practice

Guide to thalassemia healthcare professionals & patients/families

Chapters

Principles- desirable goals of centre

Guidelines- requirements of the centre

Interventions- specific steps to implement each guideline



A large graphic on the right side of the page. It features a white DNA double helix on the left, with several orange maple leaves in the foreground. The background is a blurred image of a person's face. The entire graphic is enclosed in a red border.

**Guidelines for the Clinical Care of
Patients with Thalassemia in Canada**

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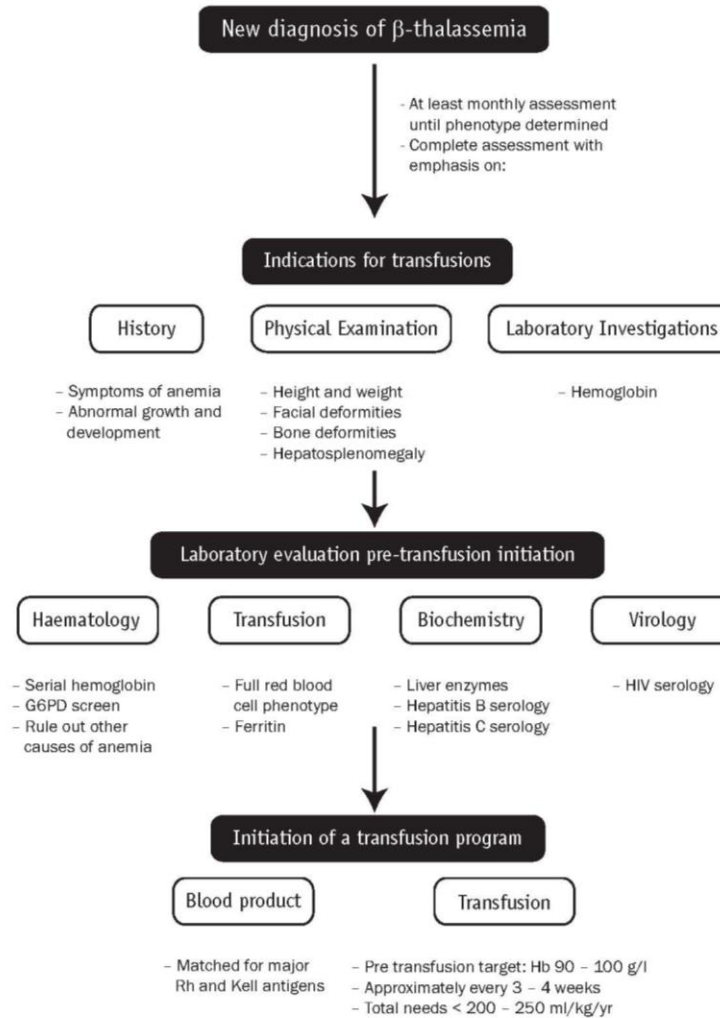


Staffing Recommendations for Satellite Clinics and Specialist Centres

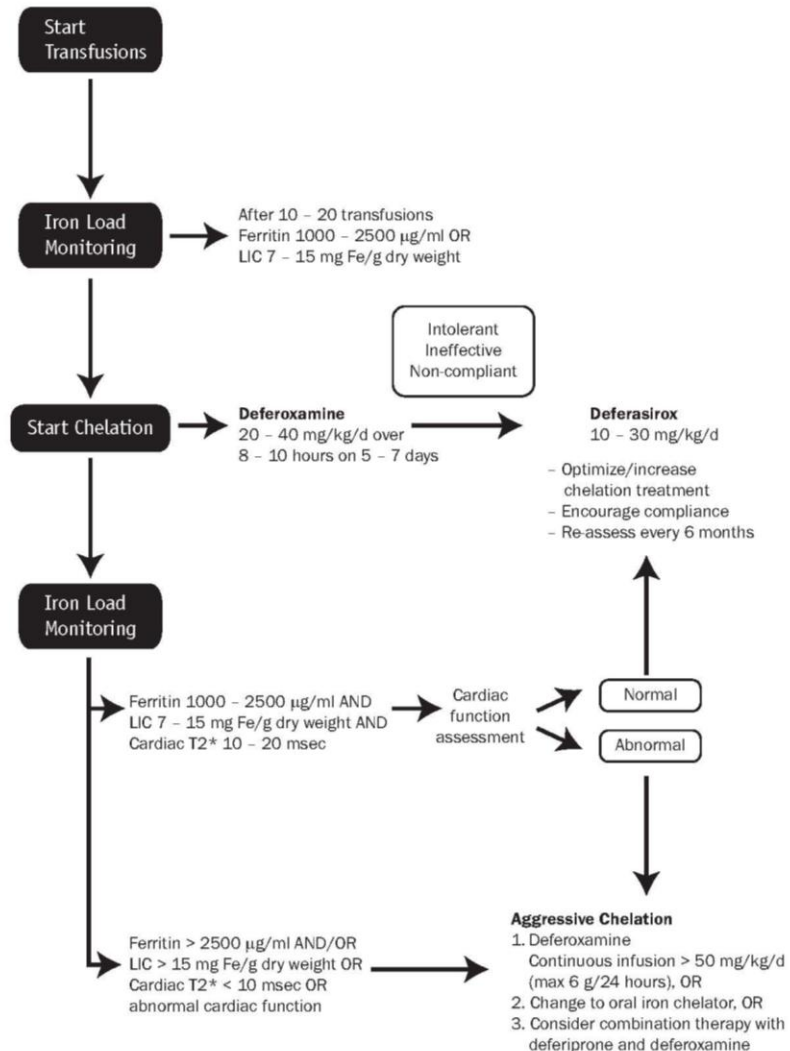
| Team Members | | Satellite Clinic | Specialist Centre |
|---|---|----------------------------|---|
| Physicians | <ul style="list-style-type: none"> • Consultant pediatric or adult hematologist (depending on age of patients) with experience in thalassemia • Pediatrician, internist, hematologist or general practitioner/ internist with knowledge of thalassemia care • On-call physicians for after-hours issues | <p>■</p> <p>■</p> | <p>■</p> <p>■</p> |
| Nursing | <ul style="list-style-type: none"> • Nurse specialist for thalassemia service: training, monitoring, co-coordinating and auditing • Registered nurses in outpatient day care unit area who can perform intravenous (I.V.) cannulation and supervise transfusions • Nurse outreach into the community: home visits, teaching pump use, etc. This may be coordinated with local home care programs • Nurse contact for patient and family | <p>■</p> <p>■</p> <p>■</p> | <p>■</p> <p>■</p> <p>■</p> |
| Access to other multidisciplinary team members | <ul style="list-style-type: none"> • Clinical psychologist • Psychologist • Social worker • Dentist • Dietician | <p>■</p> <p>■</p> <p>■</p> | <p>■</p> <p>■</p> <p>■</p> <p>■</p> |
| Access to specialist consultants | <ul style="list-style-type: none"> • Designated pediatric or adult cardiologist • Designated pediatric or adult endocrinologist • Designated pediatric or adult hepatologist • Genetic counselling • Designated obstetrician and fertility program • Bone marrow transplant service | | <p>■</p> <p>■</p> <p>■</p> <p>■</p> <p>■</p> <p>■</p> |
| Other support services | <ul style="list-style-type: none"> • Appropriate laboratory support (transfusion, diagnostic), diagnostic imaging • Access to translation services • Administrative support sufficient to ensure record maintenance and proper communication between patient and family with clinic, centre, family doctor and all services involved | <p>■</p> <p>■</p> <p>■</p> | <p>■</p> <p>■</p> <p>■</p> |



Clinical and Laboratory Aspects When Deciding Appropriateness of Initiating a Transfusion Program



Monitoring of Iron Load and Appropriate Chelation Therapy



Next steps

Implementation of guidelines

Guide for healthcare professionals

Tool to advocate for resources

Benchmark to gauge success



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