



DukeMedicine
Division of Cellular Therapy



ADULT AND PEDIATRIC BLOOD AND MARROW TRANSPLANT PROGRAM

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Monitoring Late Effects for APBMT Patients

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Author: MOORE171

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APBMT-COMM-042

MONITORING LATE EFFECTS FOR APBMT PATIENTS

1 PURPOSE

- 1.1 To describe the monitoring for late effects in Adult and Pediatric Blood and Marrow Transplant (APBMT) patients.

2 INTRODUCTION

- 2.1 Advances in hematopoietic stem cell transplantation techniques and supportive care have led to progressive improvements in long-term survival for patients undergoing hematopoietic stem cell transplantation. These patients are at risk for developing late complications related to pre, peri, and post-transplant exposures and require screening and preventative practices to maximize their overall health and quality of life.

3 SCOPE AND RESPONSIBILITIES

- 3.1 All recipients of hematopoietic stem cell transplant are at risk for developing late transplant complications.
- 3.2 Pediatric patients, in particular, are at risk for complications affecting developing organs and growth and development.
- 3.3 Physicians nurses, and advanced practice providers are responsible for ensuring that proper monitoring for follow up care is completed by an appropriate specialist.

4 DEFINITIONS/ACRONYMS

- 4.1 APBMT Adult and Pediatric Blood and Marrow Transplant
- 4.2 HSCT Hematopoietic Stem Cell Transplant
- 4.3 GVHD Graft versus Host Disease
- 4.4 TBI Total Body Irradiation

5 MATERIALS

- 5.1 N/A

6 EQUIPMENT

- 6.1 N/A

7 SAFETY

- 7.1 N/A

8 PROCEDURE

- 8.1 Patients are encouraged to be evaluated by a medical professional annually for post-transplant follow up care. Ideally, the patient should be seen by a transplant team.

- 8.1.1 The pediatric program has established a survivorship clinic focused on the evaluation and treatment of patients at risk for developing complications and/or late effects related to their therapy. Patients will be offered coordinated care through this clinic as an extension of their transplant course.
- 8.2 During an annual evaluation, the physician led team completes an age-appropriate comprehensive review of systems and physical exam with a focus on late effects and post-transplant complications related to the following organ/tissue systems:
 - 8.2.1 Immune System
 - 8.2.1.1 Infections
 - 8.2.1.2 Hypogammaglobinemia
 - 8.2.1.3 T-cell function
 - 8.2.1.4 Immunizations
 - 8.2.2 Hematologic system
 - 8.2.2.1 Anemia
 - 8.2.2.2 Thrombocytopenia
 - 8.2.2.3 Neutropenia
 - 8.2.2.4 Lymphopenia
 - 8.2.2.5 MCV
 - 8.2.2.6 Iron overload (ferritin, Fe/TIBC)
 - 8.2.3 Ocular
 - 8.2.3.1 Cataracts
 - 8.2.3.2 Sicca syndrome
 - 8.2.3.3 Microvascular retinopathy
 - 8.2.3.4 Optic nerve integrity
 - 8.2.3.5 Visual Acuity
 - 8.2.3.6 Graft Versus Host Disease (GVHD)
 - 8.2.4 Oral
 - 8.2.4.1 Sicca syndrome
 - 8.2.4.2 Dental caries
 - 8.2.4.3 Tooth agenesis
 - 8.2.4.4 Enamel dysplasia
 - 8.2.4.5 Oral cancer (especially squamous cell cancers)
 - 8.2.4.6 GVHD

- 8.2.5 Respiratory System
 - 8.2.5.1 Idiopathic pneumonia syndrome
 - 8.2.5.2 Bronchiolitis obliterans syndrome
 - 8.2.5.3 Bronchiectasis
 - 8.2.5.4 Cryptogenic organizing pneumonia
 - 8.2.5.5 Sino-pulmonary infections
 - 8.2.5.6 GVHD
- 8.2.6 Cardiac and Vascular System
 - 8.2.6.1 Cardiomyopathy
 - 8.2.6.2 Congestive heart failure
 - 8.2.6.3 Arrhythmias
 - 8.2.6.4 Valvular anomalies
 - 8.2.6.5 Coronary artery disease
 - 8.2.6.6 Cerebrovascular disease
 - 8.2.6.7 Peripheral arterial disease
 - 8.2.6.8 Hypertension
 - 8.2.6.9 Hyperlipidemia
- 8.2.7 Gastrointestinal
 - 8.2.7.1 Esophageal stricture(s)
 - 8.2.7.2 Secondary malignancies
- 8.2.8 Liver
 - 8.2.8.1 Hepatitis B
 - 8.2.8.2 Hepatitis C
 - 8.2.8.3 Iron Overload
 - 8.2.8.4 Cirrhosis
 - 8.2.8.5 GVHD
- 8.2.9 Renal and Genitourinary System
 - 8.2.9.1 Chronic kidney disease
 - 8.2.9.2 Bladder dysfunction
 - 8.2.9.3 Urinary tract infections
 - 8.2.9.4 Hypertension
 - 8.2.9.5 Vaginal stenosis
 - 8.2.9.6 Vaginal cervical, ovarian and uterine cancers

- 8.2.10 Muscle and Connective Tissue
 - 8.2.10.1 Myopathy
 - 8.2.10.2 Fasciitis/scleroderma
 - 8.2.10.3 Polymyositis
 - 8.2.10.4 Joint Contractures
 - 8.2.10.5 Chronic arthritis
 - 8.2.10.6 GVHD
- 8.2.11 Skeletal
 - 8.2.11.1 Osteopenia/osteoporosis
 - 8.2.11.2 Avascular necrosis
 - 8.2.11.3 Short stature
 - 8.2.11.4 Growth failure
- 8.2.12 Nervous System
 - 8.2.12.1 Leukoencephalopathy
 - 8.2.12.2 Late infections
 - 8.2.12.3 Neuropsychological deficits
 - 8.2.12.4 Cognitive deficits
 - 8.2.12.5 Calcineurin neurotoxicity
 - 8.2.12.6 Peripheral neuropathy
 - 8.2.12.7 Chronic pain
 - 8.2.12.8 Secondary malignancies
- 8.2.13 Endocrine
 - 8.2.13.1 Hypopituitarism
 - 8.2.13.2 Thyroid problems
 - 8.2.13.3 Central adrenal insufficiency
 - 8.2.13.4 Hypogonadism or precocious puberty
 - 8.2.13.5 Growth hormone failure
 - 8.2.13.6 Infertility
- 8.2.14 Mucocutaneous
 - 8.2.14.1 Cutaneous sclerosis
 - 8.2.14.2 Squamous cell carcinoma
 - 8.2.14.3 Genital GVHD

- 8.2.15 Psychosocial Distress
 - 8.2.15.1 Depression
 - 8.2.15.2 Anxiety
 - 8.2.15.3 Fatigue
 - 8.2.15.4 Sexual dysfunction
- 8.2.16 Secondary Malignancies
 - 8.2.16.1 AML/MDS
 - 8.2.16.2 Sarcomas
- 8.2.17 General Health
- 8.3 If a late effect is identified, the patient should be referred to an appropriate specialist for evaluation and treatment.
- 8.4 During the annual assessment the team may also screen for recurrence of primary cancer and the development of any secondary cancers.
- 8.5 During the annual assessment, the team will document:
 - 8.5.1 GVHD
 - 8.5.2 Chimerism (for allogeneic transplants)
 - 8.5.3 Immune Reconstitution until normal and patient is re-immunized
- 8.6 During the annual assessment, for patients over the age of 18, the team will advise the patient regarding:
 - 8.6.1 Education/Career
 - 8.6.2 Health insurance
 - 8.6.3 Immunizations
 - 8.6.4 Smoking
 - 8.6.5 Alcohol consumption
 - 8.6.6 Diet and physical exercise
 - 8.6.7 Sun exposure
 - 8.6.8 Cancer Screening
 - 8.6.9 Mammograms at Age 25 for those who received radiation
 - 8.6.10 Colonoscopy at age 30 for those who received radiation
 - 8.6.11 Prostate screening
- 8.7 During the annual assessment for pediatric patients, the team will advise the patient and caregiver regarding:
 - 8.7.1 School Performance
 - 8.7.2 Growth
 - 8.7.3 Pubertal development

- 8.7.4 Dental issues
- 8.7.5 Cataract screening
- 8.7.6 Thyroid screening

8.8 If deemed necessary, patients under the care of the pediatric transplant care team will be considered for transition to adult care. At such time, the pediatric team will consult with the adult care team to coordinate transition of care. Copies of all relevant health information will be provided to the accepting health care team to ensure continuity of care and will include, but is not limited, to a summary of the patient's past medical history, pre-transplant workup, conditioning, transplant, engraftment status, and post-transplant course to date.

9 RELATED DOCUMENTS/FORMS

- 9.1 Adult patients attend a discharge education class. Slides for that presentation are updated regularly based on evidence-based practice and process.
- 9.2 Pediatric patients/caregivers are given a Discharge Handbook and receive individual teaching for their child's needs by the PBMT Discharge Planner.
- 9.3 Be The Match® After Transplant Care Toolkit (print copy with instructions for mobile application).

10 REFERENCES

- 10.1 NMajhail, JRizzo, SLee, MAJurf, YAtsuta, CBonfim, LBUrns, NChaudhri, et al; Recommended Screening and Preventive Practices for Long-term Survivors after Hematopoietic Cell Transplantation; Biol Blood Marrow Transplant. 2012 March; 18(3); 348-371. Doi:10.106/j.bbmt.2011.12.519

11 REVISION HISTORY

Revision No.	Author	Description of Change(s)
05	MC Author: McCollum	Section 8.1 and 8.3 minor wording rearrangement for clarity.
	SME: Jerelyn Moffett	Section 8.6.9 and 8.6.10 - added "radiation" requirement
		Section 8.7.6 - clarified thyroid screening for all patients
		Section 9.2 Added Individual teaching

Signature Manifest

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Name/Signature	Title	Date	Meaning/Reason
Sally McCollum (MOORE171)		12 Jun 2023, 04:16:18 PM	Approved

Management

Name/Signature	Title	Date	Meaning/Reason
Nelson Chao (CHAO0002)		14 Jun 2023, 08:51:47 PM	Approved

Medical Director

Name/Signature	Title	Date	Meaning/Reason
Joanne Kurtzberg (KURTZ001)		14 Jun 2023, 09:32:29 PM	Approved

Quality

Name/Signature	Title	Date	Meaning/Reason
Bing Shen (BS76)		16 Jun 2023, 07:19:13 PM	Approved

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Betsy Jordan (BJ42)		18 Jun 2023, 10:52:22 AM	Approved