



PEDIATRIC BLOOD AND MARROW TRANSPLANT PROGRAM

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PBMT-GEN-035
POLICY FOR REFERRING PHYSICIANS FOR PATIENT
DISCHARGE AND FOLLOW-UP

1 PURPOSE

- 1.1 To describe the methods used to communicate with referring physicians and other health career professionals regarding patient discharge and follow-up.

2 INTRODUCTION

- 2.1 Transplant patients undergo a complex and risky procedure at the transplant center. At the time that they are discharged to home, they continue to have ongoing complex medical issues, need to continue to avoid exposure to opportunistic infections, continue to take medications for Graft versus Host Disease (GvHD) and infection prophylaxis which require monitoring and dose adjustments and require long-term follow-up for late effects.
- 2.2 This procedure describes the methods of communication between the transplant center and the referring physician(s) to ensure that they remain an integral part of the patient's care team and to be sure that they are fully informed regarding the type of care the patient will require when they return home.

3 SCOPE AND RESPONSIBILITIES

- 3.1 Multidisciplinary: The physician, and or designee such as an Advance Practice Provider, is the main discipline responsible for the care of the PBMT patient including processes around discharge and transfer of care. Therefore (s)he is responsible for oversight of all aspects outlined in this procedure.
- 3.2 Other disciplines, such as nursing staff, clinical social workers, pharmacists, and dieticians may be asked to participate in discharge/transfer processes, as needed.

4 DEFINITIONS/ACRONYMS

- 4.1 GvHD Graft versus Host Disease
- 4.2 HSCT Hematopoietic Stem Cell Transplant
- 4.3 H&P History and Physical
- 4.4 IVIG Immune globulin, intravenous
- 4.5 PBMT Pediatric Blood and Marrow Transplant
- 4.6 TPN Total Parenteral Nutrition

5 MATERIALS

- 5.1 NA

6 EQUIPMENT

- 6.1 NA

7 SAFETY

7.1 N/A

8 PROCEDURE

- 8.1 All patients remain under the care of the transplant center until the patient is:
 - 8.1.1 Resolved of acute medical problems
 - 8.1.2 On a stable medication regimen
 - 8.1.3 Transfusion independent
 - 8.1.4 On a stable schedule of regular transfusions
 - 8.1.5 Controlled in GvHD treatment - if present
 - 8.1.6 On a stable regimen of oral/enteral feeding and/or Total Parental Nutritional (TPN), as required
 - 8.1.7 Under the care of a caregiver who is comfortable with the discharge plan.
- 8.2 Additional requirements for discharge include assurance that the local caretaker can provide the care and support that is required, including but not limited to:
 - 8.2.1 The referring physician must be able to provide access to medical care 24/7 for the patient.
 - 8.2.2 Irradiated, leukocyte-depleted blood products must be available to the patient on a routine and emergent basis.
 - 8.2.3 Transplant-related medications/IVIG (immune globulin intravenous), GvHD medications must be available or the patient must be willing to return to the transplant center on a regular basis to receive these therapies.
 - 8.2.4 Drug levels (e.g. cyclosporine/tacrolimus), routine chemistries, counts, liver and renal function tests must be available in a timely fashion.
 - 8.2.5 Any ancillary therapies ongoing on a regular basis must be available in or near the patient's local community.
 - 8.2.6 If home care is needed, the local homecare agency is available and will be contacted by a member of the medical team. Documentation pertaining to transplant course will be communicated appropriately.
- 8.3 In the event that a patient requires discharge/transfer of care prior to engraftment the following additional considerations will also be incorporated into the discharge process:
 - 8.3.1 A consultation with the receiving physician and or designee regarding ongoing care including but not limited to:
 - 8.3.1.1 Management of nausea and vomiting
 - 8.3.1.2 Management of pain and other discomforts

- 8.3.1.3 Monitoring of blood counts and possible need for transfusions of blood products
 - 8.3.1.4 Monitoring of organ dysfunction or failure and institution of treatment
 - 8.3.1.5 Monitoring of graft failure and institution of treatment
 - 8.3.1.6 Regular assessment for evidence of acute and chronic GvHD
- 8.3.2 Availability of facilities that provide appropriate location, adequate space and protection from airborne microbial contamination.
- 8.3.3 Access to the following, as required, by the recipient:
 - 8.3.3.1 Appropriate medications
 - 8.3.3.2 Blood products
 - 8.3.3.3 Any additional care specific for that individual patient
- 8.4 Routine, uncomplicated patients undergoing autologous transplantation typically return home to the care of their referring physician between 60-100 days post-transplant.
- 8.5 Routine, uncomplicated patients undergoing allogeneic transplantation from an HLA-matched sibling, without active GvHD, typically return home to the care of their referring physician between 60-100 days post-transplant.
- 8.6 Routine, uncomplicated patients undergoing allogeneic transplantation from an unrelated adult or umbilical cord blood donor, without active GvHD, typically return home to the care of their referring physician between 120-140 days post-transplant.
- 8.7 Patients with complications, including but not limited to, GvHD, recurrent or ongoing active infections, organ dysfunction, feeding intolerance, remain near the transplant center under their care until these problems stabilize and the criteria outlined in section 1 are met.
- 8.8 Records Management for communications with referring physicians:
 - 8.8.1 A series of documents and letters are provided to the referring physician(s) on a regular basis.
 - 8.8.2 In addition, copies of daily notes are emailed, faxed or mailed to the referring physician on a weekly basis.
 - 8.8.3 Referring physicians are queried to determine their preferences for communication, i.e. phone, email, fax, mail, and these preferences are recorded and honored whenever possible. Specific scheduled written communications with the referring physician are detailed below.
 - 8.8.4 The results of the patient's pre-transplant work-up, a document which summarizes their current history, past medical history, review of systems, infectious disease status, exposure risks, results of the pre-transplant work-up including disease status, organ function, infectious status, colonization status, plans for cytoreduction, supportive care,

GvHD prophylaxis (if allogeneic transplant) and all procedures are outlined in this summary (i.e. H&P document). This is sent to the referring MD shortly before the admission of the patient to the Pediatric Blood and Marrow transplant (PBMT) unit.

- 8.8.5 Referring physicians with access to the medical record may view patient progress during the inpatient and outpatient course through CareEverywhere technology. If the referring physician does not have access to the records, records may be sent to referring teams when needed.
- 8.8.6 The discharge summary is sent to the referring physician when the patient is discharged from the inpatient unit.
- 8.8.7 A "going home" letter is sent when the patient is discharged back to the care of their referring physician. This letter summarizes the patient's past medical history, pre-transplant work-up, conditioning, transplant, post-transplant complications, engraftment and chimerism, infections, GvHD, and in and outpatient care at Duke. In addition, isolation and infectious disease precautions, transfusions practices, vaccine guidelines and guidelines for management of medications and supportive care are provided. The dates of the patient's next appointment at Duke are also specified. Routine and emergency contact information for the PBMT program and the patient's primary PBMT physician and nurse practitioner are provided. The physician is also called by a PBMT physician or nurse practitioner to confirm all necessary arrangements for patient follow-up at home.
- 8.8.8 The patient is re-evaluated at Duke at quarterly intervals for the first year post transplant and a minimum of yearly for the first six years after transplant. Subsequent visits are determined based on patient status and access to local care in their home community, targeting a schedule of annual visits with their local care team followed by visits with the PBMT team every 2 years. Summary letters of studies performed and plans for treatment and follow-up until the next scheduled visit are provided in a summary letter to the referring physician. At these visits, the patient's disease status, chimerism, organ function, growth and development, school performance, GvHD status, risk for cataracts, risk for avascular necrosis and access to medical care and follow-up are evaluated. Late effects, particularly those involving growth, endocrine function, cognitive function and sterility are particularly important in children s/p Hematopoietic Stem Cell Transplant (HSCT).
 - 8.8.8.1 Copies of all test results and letters will be copied and sent to the patient/parents/guardian on a routine basis.

9 RELATED DOCUMENTS/FORMS

9.1 NA

10 REFERENCES

10.1 N/A

11 REVISION HISTORY

Revision No.	Author	Description of Change(s)
04	Sally McCollum	<ul style="list-style-type: none">• Scope Section- expanded to include multidisciplinary roles.• Section 8.8.5 – Added to reflect access to records• Section 8.8.8 – Updated to reflect current follow-up timeline.

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