



Appendix

Title	Greater Manchester Cancer Myelofibrosis Patient Pathway
Author & Owner	Greater Manchester Cancer

Version Control		
Version/ Draft	Date	Revision summary
1.0	30.07.2018	Initial draft for review
2.0	27.09.2018	Approved

Pathway Details/Supporting Information

The Myelofibrosis pathway also incorporates the supportive and palliative care pathways. Key discussion points, contacts with the Key Worker, holistic assessment points and key information points are identified by symbols along the pathway. The Patient Information Pathway supports the steps in the Myelofibrosis pathway such as referral, diagnostic procedures and tests, diagnosis, treatments, side effects and support services. Additional national resources or information to meet patient/carer needs may be offered at any stage along the pathway.

a) First Appointment

- Patient is seen in OPD clinic, ward or Haematology Day Unit depending on clinical need.

Investigations: FBC and film, biochemical profile, haematinics, LDH and JAK2/CALR/MPL mutation on peripheral blood, and bone marrow aspirate, trephine & cytogenetics. Where a full consideration of prognosis is clinically essential (where patient is suitable for allogeneic stem cell transplantation) extended myeloid mutation genotyping (e.g. ASXL1, EZH2, TET2, IDH1/IDH2, SRSF2, SF3B1) is required. Consider serum erythropoietin and abdominal ultrasound or CT scan, the latter especially if splenectomy is under consideration.

b) Specialist MDT Discussion

- Patient treatment plan/management plan discussed at relevant Specialist Haematology MDT (listed below) in line with Manchester Cancer guidelines:
Central Sector (Manchester Foundation Trust)
North East Sector (Royal Oldham)
North West Sector (Salford Royal, Bolton, Wrightington, Wigan & Leigh)
South Sector (The Christie, East Cheshire, Stepping Hill, Tameside)
- Participation in clinical trial to be considered where available
- If 16-18 years old refer patient to the Teenage and Young Adult Unit (TYA) at The Christie. If 19-24 years offer the option of referral and a visit to The Christie and follow the Teenage and Young Adult with cancer pathway

c) Consultation for Diagnosis

- Patient attends clinic or is seen on ward/day unit to discuss diagnosis and treatment plan
- Clinical trial options discussed with patient
- Holistic assessment undertaken at diagnosis, disease progression or change in circumstances
- Breaking Bad News – CNS and family/carer to be present where possible
- Contraception and fertility issues to be discussed and referral to Reproductive Medicine Unit made as appropriate
- Discussion around tissue typing of patient and siblings (if appropriate)
- GP to be informed of cancer diagnosis within 24 hours of discussion with patient
- Patient to be offered summary of the consultation at which the treatment options were discussed.
- Patients should have access to information in different formats as appropriate i.e. written / video / different languages / for those with visual/hearing impairment etc.

- Patients to be offered copies of letters sent to their GP

d) First Definitive Treatment

- Active monitoring.
- Supportive care with transfusions and growth factor support.
- Splenectomy.
- Outpatient based cytoreductive treatment.
- Outpatient based JAK2 inhibitors.
- Allogenic stem cell transplant.
- Clinical trial if available/appropriate.
- Palliative Care

e) Survivorship

Provide treatment summaries for people with Myelofibrosis (and their GPs); as treatment is on-going over longer periods consider annual treatment summary. Discuss these with the patient, highlighting personal and general risk factors, including late effects related to their treatment.

Regular review of patient's symptomology is an important part of assessment for patients with myelofibrosis and can aid in treatment decisions.

Provide information to people with Myelofibrosis during the course of treatment about how to recognise possible disease progression and transformation and advise on late effects of current/previous treatment.

Provide information book on myelofibrosis (e.g. from Bloodwise, Macmillan); refer patient to MPN Voice online website for support and further information.