



Appendix

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

Version Control		
Version/ Draft	Date	Revision summary
1.0	28.04.2019	Initial draft for review
2.0		Approved

Pathway Details/Supporting Information

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 MDS 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

- All 2WW referrals are to be seen within 7 days and the latest within 14 days of referral
- Teenage and young adults are seen within 48hrs of referral

b) Diagnosis

- Investigations include FBC, blood film, biochemical profile, LDH, Urate, B12/Folate, Ferritin, EPO levels and in suitable patients a bone marrow aspirate, trephine with cytogenetics/FISH and a molecular panel (NGS).

b) Specialist MDT Discussion

- Patient treatment plan/management plan discussed at relevant Specialist Haematology MDT (listed below)
Central Sector (Manchester Foundation Trust)
North East Sector (Pennine Foundation Trust/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 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 should be offered to receive copies of all letters sent to their GP

d) First Definitive Treatment

- Introduce patient to day unit facilities/team for transfusion support and start iron chelation as appropriate

early in the process

- District nurse referral or teach patient/carer to self administer EPO/GCSF
- For administration of azacitidine (hypomethylating agents) introduce patient to day unit facilities/team or book for home administration as appropriate
- Consider admission or referral to a haematology designated ward (BCSH level 2b) for intensive chemotherapy
- Clinical Trial if available/appropriate
- Refer early for stem cell transplant opinion if suitable

e) Survivorship

Provide treatment summaries for people with MDS (and their GPs); as treatment is on-going over longer periods consider one treatment summary every 2 years. Discuss these with the patient, highlighting personal and general risk factors, including late effects related to their treatment.

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