MDS UK
Supporting Patients with Bone Marrow Failure
www.mdspatientsupport.org.uk

Factsheet for
GP's - General Practitioners

MDS: ANAEMIA MIGHT BE THE FIRST CLUE

DIAGNOSE ANAEMIA – SUSPECT MDS

Myelodysplastic Syndromes – Basic Facts

Myelodysplastic Syndrome (MDS) is **one of the most common bone marrow failure conditions.**[1]

Most of the patients are diagnosed at the age of 71 but it can also be diagnosed in younger patients.

Approximately 2,000-3,000 new cases of MDS are diagnosed each year in the UK.[2]

This puts the number of new MDS cases very close to the number of those newly diagnosed with acute myeloid leukemia (AML). Patients with MDS are at **increased risk for transformation to AML** and many patients suffer from long term blood transfusions, anaemia, infections, bleeding and complications related to excessive iron accumulation.

A majority of MDS patients are first seen by their primary care physicians and the **disease manifestations can be quite variable** which delays diagnosis and subsequent institution of correct treatment. It is likely that a general practitioner (GP) or a primary care physician (PCP) will encounter 1-2 cases of MDS during their practice.

To assist in raising awareness among GPs or PCPs of MDS as a possible diagnosis, this decision support tool has been prepared by the Medical Advisory Board of the Aplastic Anemia & MDS International Foundation and adapted for the UK by MDS UK Patient Support Group.

GPs or PCPs who think they have a patient who may have a potential diagnosis of MDS are urged to refer to a haematologist with expertise in the diagnosis and treatment of this condition.

CLINICAL MANIFESTATIONS OF MDS

Most patients with MDS will **not** present with any **signs and symptoms at the time of their initial presentation**. Most of them will **have chronic low red blood counts, white blood cell counts and/or platelet counts, or persistence of abnormalities on repeat tests.** More often, all three blood components are low but sometimes it could be a single or combination of abnormal blood counts. On occasion, some patients will present with abnormal looking cells in their blood stream called "dysplasia" or immature cells called "blasts".

If patients do present with clinical symptoms and signs, they are usually related to anemia. **The most common anaemia associated symptoms and signs include fatigue, exercise intolerance, palpitations, weakness, headaches, dyspnea on exertion, chest pain, lightheadedness, and dizziness.**

Occasionally patients can present with fever, chills, and pulmonary infections due to persistently low white blood cell counts or with bleeding related to low platelet counts.

WHY WOULD YOU SUSPECT SOMEONE HAS MDS ?

An elderly patient who has persistently low blood counts or requiring blood transfusions that cannot be explained by other common causes should raise the suspicion for MDS.

If the patient has:

- Unexplained cytopenias or monocytosis,
- Unexplained red blood cell macrocytosis (elevated mean cell volume – MCV),
- Atypical cells in the peripheral blood
  - Immature cells such as blasts or myelocytes, hypogranular platelets or neutrophils, dysplastic cells, or pseudo-Pelger-Huet (2-lobed neutrophils)

If the full blood count doesn't make sense, consider the possibility of a myelodysplastic syndrome (MDS). MDS is treatable and contemporary treatments can improve quality of life, delay disease progression, and extend survival.
Please discuss these worrisome blood findings and refer these patients to a haematologist.

References and further reading

1. Sekeres MA. Epidemiology, natural history, and practice patterns of patients with myelodysplastic syndromes in 2010. J Nat'l Compr Canc Netw. 2011 Jan;9(1):57-63.
2. Aul C, Germing U, Gattermann N, Minning H Department of Internal Medicine, Heinrich Heine University, Düsseldorf, Germany. Leukemia Research [1998, 22(1):93-100]
- Atallah E, Garcia-Manero G. Treatment strategies in myelodysplastic syndromes. Cancer Invest 2008; 26: 208–216.
- Haematological Malignancy Research Network (HMRN) http://www.hmrn.org/Home.aspx accessed February 2011

Further assistance for your MDS patients

If you have a patient who has been diagnosed by a haematologist – and are seeking further information, please try these further resources:

For clinicians:
BHS (British Haematology Society) Guidelines
NICE guidance on MDS treatment
UK MDS Forum – Guidelines and trials available - www.ukmdsforum.org
MDS Foundation website – www.mds-foundation.org
AA&MDS International Foundation - www.aamds.org

For patients:
MDS UK Patient Support Group offers help, support and information material.
MDS UK sends out information packs, organises patient information events and regular regional coffee mornings. The patient friendly website is vetted by MDS specialists.

A MDS UK leaflet and newsletter is available for GP's to order and hand out to patients.

MDS UK Patient Support Group
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KEY QUESTIONS TO ASK A PATIENT WHEN YOU SUSPECT MDS

While a patient may show no symptoms, further investigation can often be initiated following an abnormal complete/full blood count (CBC/FBC).

ANAEMIA SYMPTOMS

Do you have the following? For how long?

- Fatigue?
- Weakness?
- Malaise?
- Dyspnea on exertion
- Dizziness/lightheadedness?
- Cognitive Impairment? (Difficulty thinking or concentrating)?

LEUCOPENIA/THROMBOCYTOPENIA SYMPTOMS

Do you have the following? How often?

- Repeated infections?
- Unexplained fever?
- Bleeding gums, blood in your urine or do you bruise easily?

GENERAL

- Have lost weight unintentionally?
- Are you anorexic?

PAST MEDICAL HISTORY

- Have you ever been treated with chemotherapy or radiation?
- Have you required blood transfusions?
- Have you worked with chemicals or radiation in the past?
- Have you ever been told you had a blood disorder?
- Have you had low blood counts before that were unexplained?

PHYSICAL

While there are often no physical findings, check for:

Tachycardia, pallor, splenomegaly, petechiae, painless adenopathy

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This Factsheet was produced by an international working group of MDS Patient Advocacy Groups.

This Factsheet is for the UK and available from the MDS UK Patient Support Group:

www.mdspatientsupport.org.uk

DIAGNOSING MYELODYSPLASTIC SYNDROMES (MDS)

Suspect MDS

Most Common Presentation

- Usually asymptomatic at presentation
- Most patients will be diagnosed based on abnormal blood counts:

1. Anaemia +/- high MCV
2. Low WBC
3. Low neutrophil counts
3. Low platelet counts
4. “Blasts” in the peripheral blood smear
5. “Dysplastic cells” in the peripheral blood

Other Common Clinical Features

- Age >60 years
- Chronic blood transfusions
- Symptoms and signs related to anaemia: Fatigue, weakness, dyspnoea on exertion, tachycardia, palpitations, dizziness, chest pain, exercise intolerance, cognitive impairment, dizziness, lightheadedness

Less Common but Possible Presentations of MDS

- Unexplained fever
- Unexplained weight loss
- prior exposure to chemotherapy or radiation therapy
- Bleeding
- Infections
- Autoimmune manifestations like peripheral neuropathy, cutaneous vasculitis, myositis, pleural effusions
- Splenomegaly, hepatomegaly or lymphadenopathy
- Cutaneous findings like Sweet’s syndrome or myeloid sarcoma

Initial Work-up

- Detailed History and physical examination
- Full blood count with differentials, reticulocyte count
- Complete metabolic panel – including liver function test, uric acid, phosphate
- **Rule out nutritional causes:** serum vitamin B12, serum folate, iron studies, thyroid function tests
- **Rule out causes of increased destruction:** LDH, haptoglobin, direct Coomb’s test, peripheral blood smear
- **Rule out sequestration:** Ultrasound of the spleen

Differential Diagnosis

- **Nutritional Causes:** Deficiencies of Vitamin B12, folate, iron, copper, zinc, pyridoxine
- **Increase peripheral destruction :** haemolytic anaemia, haemoglobinopathies
- **Decreased BM production:** Myeloproliferative neoplasms like myelofibrosis, lymphoid cancers
- **Others: Infections (HIV, parvovirus, hepatitis B & C), medications, connective tissue or autoimmune diseases, anaemia of inflammation or renal disease**

Refer all patients with suspected MDS to a haematologist who has an expertise in the diagnosis and management of patients with bone marrow failure or MDS.