**RAEB 1 and 2 constitutes about 40% of all MDS cases. For many people, MDS can remain stable for many years causing few symptoms. For others, it may progress rapidly into a different subtype of MDS or transform into an acute leukaemia.**

**What is MDS?**
Myelodysplastic syndrome (MDS) is a group of diseases that affects, to a greater or lesser extent, the production of normal blood cells in the bone marrow. In MDS, abnormal bone marrow stem cells produce increased numbers of immature blood cells. These cells do not grow properly and often die prematurely. This results in fewer red blood cells, white blood cells and platelets being produced. The most immature blood cells are called *blasts* and the higher the number of blasts, the greater the chance of MDS progressing to an acute leukaemia.

**What is RAEB?**
RAEB stands for Refractory Anaemia with Excess Blasts. In RAEB, blast numbers are higher than normal. RAEB type 1 (RAEB-1) and type 2 (RAEB-2) together constitute about 40% of all MDS cases. RAEB is separated into these two categories because of the differences in survival and chance of the disease progressing to an acute leukaemia. People with RAEB may have one, two or all three of the following problems with blood cell production:

- **Refractory anaemia:** a decrease in the number of circulating red cells, resulting in symptoms of anaemia.
- **Refractory neutropenia:** a decrease in a type of white blood cell called neutrophils. When these fall below normal limits, the patient is then considered 'neutropenic' and susceptible to infections.
- **Refractory thrombocytopenia:** a decrease in the number of platelets, leaving the person susceptible to severe bruising and bleeding. Platelet quality also may be affected, increasing the bleeding tendency even though the platelet numbers are relatively normal.

**What is the risk RAEB will transform to acute myeloid leukaemia (AML)?**
MDS is classified as *low risk, intermediate-1 and intermediate-2 or high risk* according to the International Prognostic Scoring System (IPSS) at diagnosis. This system predicts the risk of your disease transforming into an acute leukaemia or your likely prognosis. The score is calculated on the bone marrow blast (immature) cell count, number of blood cell types affected and number and type of genetic changes on a cellular level.

Most people with RAEB will fall into the intermediate-1, intermediate-2 or high risk categories. The RAEB-1 type of MDS transforms to an acute leukaemia in approximately 25% of cases. The RAEB-2 type of MDS transforms to an acute leukaemia in approximately 33% of cases. Signs that the disease may be progressing include frequent infections, bleeding (e.g., from the nose or gums), bruising, and the need for more frequent blood transfusions.

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Do we know what causes MDS?
We do not know the cause of most cases of MDS. We do know, however, that MDS occurs as a result of gene mutation at a cellular level. Any incident that damages the genetic material of the body can potentially cause a mutation that in turn may contribute to the development of MDS. Examples of these incidents may include:

- Ageing
- Chemicals
- Cigarette smoking
- Radiation
- Obesity
- Pre-existing bone marrow condition
- Cytotoxic chemotherapy
- Rare genetic or family history

MDS is not infectious and cannot be transmitted from one person to another.

Who does RAEB affect?
The majority of people diagnosed with MDS are over the age of 50. However, MDS can occur at any age.

How is RAEB treated?
Standard treatment for high risk MDS patients is azacitidine (Vidaza®) and supportive care. In some people, it may be appropriate to first 'watch and wait' to see if there are any changes or progression of the disease.

Demethylating agents such as azacitidine have improved treatment for people with MDS. This works by suppressing the gene expression that allows cancer cells to grow unimpeded.

- In clinical trials these medications have been shown to induce complete or partial remissions, hence improving outcomes. They are now considered standard treatment.
- They are given as a subcutaneous injection under the skin. There are side-effects associated with the use of these types of medications, which may actually lead to an increased need for supportive care initially.

Watch and Wait
involves regular monitoring of blood and general health. No intervention is needed unless the person begins to develop signs and symptoms of the disease that indicate it is progressing.

Supportive care
is the mainstay of treatment for the majority of people with side-effects. Supportive care is aimed at managing symptoms of the condition and improving the person’s quality of life. It can make the person feel better without actually reversing the disease or preventing it from progressing. Supportive care therapies may include:

- Blood and platelet transfusions – MDS may lead to a reduction in the number of circulating blood cells. Transfusing blood products may be required to alleviate symptoms and to improve overall health and to minimise the risk of bleeding.
- Antibiotics – people who have a reduced immune system from MDS may be at an increased risk of developing severe infection. Antibiotics can prevent a simple infection becoming life-threatening. It is important to note: if you have a fever above 38 degrees, contact your doctor or hospital.
- Iron chelation therapy – red blood cells contain iron and when people with MDS require ongoing blood transfusions, they can build up excess iron in their bodies (iron overload) which can be damaging to body organs. Therapies may be administered that help remove the excess iron from the body.

Supportive care may be the most appropriate treatment for older people or those with other health problems. This is mainly due to this group of people being unable to tolerate the stronger treatments used for MDS. Supportive care does not aim to treat the disease but can help alleviate symptoms such as shortness of breath, bruising or bleeding.

Continues...
Chemotherapy treatment in MDS is generally used to treat a rising white cell count. It may also be used if the MDS has transformed to a type of acute leukaemia.

- Chemotherapy works by decreasing the number of circulating blast cells (leukaemia cells) in the bone marrow. When effective, it can allow the stem cells to resume manufacturing normal red and white cells and platelets for a period of time.

Is there a cure?
For younger people, a stem cell transplant is an option and is the only known cure for MDS, however, is only a suitable treatment option for a small number of people with MDS. Your doctor will discuss all treatment options suitable to your particular situation with you and your loved ones and gain your consent prior to the commencement of any treatment.

How do clinical trials help?
Treatments are being revised regularly as new research becomes available. Research in the laboratory opens the possibility for clinical trials in the hospital setting. This may give a person access to new treatments before being otherwise available and approved by the government. Clinical trials have specific criteria to ensure the safety of the person from the new treatment; this then helps to ensure credible results. Through clinical trials, people can help others by contributing to medical research and future treatments.

The Leukaemia Foundation publishes the guides: Understanding MDS - A guide for patients & families; Understanding Allogeneic Transplants; and the fact sheet: Clinical Trials: Latest treatments and best options.

For further information, freecall 1800 620 420
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