Myeloma: an introduction for newly diagnosed patients

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This talk will cover…

• What is myeloma
• What causes myeloma
• Initial treatment
Three take home messages

1. Myeloma is a cancer arising from abnormal plasma cells in the bone marrow
2. The causes of myeloma are not fully understood
3. Treatment aims to:
   - Prolong life
   - Prevent damage to the body
   - Achieve the best quality of life
Who’s in the room?

Vote:  

Q1: Do you have myeloma?

Q2: Do you have a family member or friend with myeloma?

Q3: Are you on treatment for myeloma?
What is myeloma?

Antibodies help fight infection.

Paraprotein: antibody with no use in the body.

Bone marrow.
Causes of myeloma

- Inherited risk
- Parents

- Acquired risk
- Environment
- Chemicals
Myeloma – risk factors

**AGE** mainly occurs in over 65

**GENDER** more men than women

**ENVIRONMENT**

**RACE** more prevalent in those of African descent

**FAMILY HISTORY** immediate family members incidence is 10 in every 100,000 compared to 5 in every 100,000

**MGUS**
What’s typical?

It’s very hard to say:

- **Spectrum** from MGUS, smouldering myeloma through to symptomatic myeloma
- **Very individual** – no two patients alike
- Different **subtypes** of myeloma (type of paraprotein, light chain, non-secretory, genetic subtype)

However, all myeloma is relapsing-remitting
Relapse and remission

- Symptomatic disease requiring treatment
- Relapse
- Relapse
- Relapse

Paraprotein level

- MGUS asymptomatic myeloma
- 1st remission or plateau
- 2nd remission or plateau
- 3rd remission or plateau

Treatment

Myeloma UK
How myeloma affects the body

- Fatigue
- Breathlessness
- Kidney damage
- Recurring infections
- Bone pain
Treatment decisions

• When treatment begins depends on test results, symptoms, complications and individual factors

• Agreement between doctor and patient when to start treatment

• If treatment not yet needed:
  • Actively monitored
  • Be vigilant for symptoms
Aims of treatment

- Improve quality of life
- Prolong life
- Balance risks versus benefits

Side-effects from treatment

Control disease
Reduce symptoms
Types of treatment

- Chemotherapy
- Steroids
- Immunomodulatory drugs
- Proteasome inhibitor
- High-dose therapy and stem cell transplant
- Histone deacetylase inhibitors

Anti-myeloma treatment

Supportive treatment

- Bisphosphonates
- Erythropoietin
- Antibiotics
- Radiotherapy
- Balloon kyphoplasty
- Percutaneous vertebroplasty
- Pain-relief
Initial treatment

**YOUNGER AND/OR FITTER**

- INITIAL TREATMENT
  - HIGH DOSE TREATMENT (HDT)
  - CLINICAL TRIALS
  - STEM CELL TRANSPLANT (SCT)

**OLDER AND/OR LESS FIT**

- STANDARD / LOWER DOSE TREATMENT

**ELDERLY AND FRAIL**

- +/- APPROPRIATE SUPPORTIVE TREATMENT
Common initial treatment combinations

<table>
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<th>Combination</th>
<th>Chemotherapy</th>
<th>Steroid</th>
<th>Other</th>
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<tr>
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<td></td>
<td>Dexamethasone</td>
<td>Velcade, Thalidomide</td>
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<tr>
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<td>Cyclophosphamide</td>
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<td>Thalidomide</td>
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<td>Melphalan</td>
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- Exact combination depends on various factors
- Clinical trials may offer different combinations
Who’s in the room?

Vote:  

Q1: Who has been told they are likely to have high-dose therapy and a stem cell transplant (HDT-SCT)?

Q2: Has anyone started this process?

Q3: Has anyone already had HDT-SCT?
HDT – SCT process

1-2 WEEKS
Mobilisation, collection and storage of stem cells

2-3 WEEKS
Treatment with high-dose chemotherapy
Recovery of bone marrow function

STEM CELLS RETURNED TO THE BLOOD (TRANSPLANT) AND RESTORED IN THE BONE MARROW (ENGRAFTMENT)

Variable, typically 3-6 MONTHS
General recovery, supportive care, regular outpatient appointments
Treatment response

• Test are carried out regularly to measure response to treatment
• Treatment response defined as
  • **Remission**
  • **Plateau** or **stable disease**
• Duration of response can be important as the level of response
• Improvement in symptoms and complications also important
Maintenance treatment

PARAPROTEIN LEVEL

ACTIVE MYELOMA

MGUS ASYMPTOMATIC MYELOMA

1ST REMISSION OR PLATEAU

MAINTENANCE TREATMENT

INITIAL/FIRST-LINE TREATMENT

TREATMENT

RELAPSE
Your role in treatment

Choice
- Ask questions
- Be aware of the risks/benefits

Be vigilant
- Report pain, fatigue, tingling, sore gums, weight loss to your clinical nurse specialist (CNS) or doctor

Compliance
- Don’t stop taking treatment because of side-effects, consult your doctor
Importance of information

• Helps you to come to terms with your diagnosis
• Provides a sense of control
• Helps you to make informed decisions about treatment and care
• Strengthens the patient-family-nurse-doctor partnership

Visit the Myeloma UK Patient Information stand during the break
“After the initial shock of being hit with the myeloma sledgehammer, keep positive – it’s not the end of the road.”

“Make an effort to tell your family and friends and encourage them to continue to talk to you. Becoming isolated is the last thing you will want and need.”

“Your myeloma is as unique as you are and no two cases will have the same needs or outcomes.”

Tips featured in *The small things that make all the difference* book
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Myeloma UK information and support services

- Myeloma Infoline: 0800 980 3332
- Online Discussion Forum
- Information on Myeloma TV and the Myeloma UK website
- Myeloma and Haematology Support Groups
- Patient and Family Infodays
- Printed Patient and Family Information
Myeloma UK resources

Online and printed information about myeloma

Videos featuring patients and healthcare professionals

3D animations about myeloma
Thank you

Any questions?
Here for everything a diagnosis of myeloma brings

Support available at:
www.myeloma.org.uk  0800 980 3332