

The Patient and Family Experience

Wessex and South West
Survivorship Learn and Share Event

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Structure of talk

- Nature of myeloma
- Impact on patients and carers
- Perspectives and perceptions of treatment
- Implications of treatment
- How Myeloma UK addresses these issues and challenges
- Summary



About myeloma

- Treatable but not curable
- Complex and debilitating
- Relapsing and remitting
- Very individual – spectrum of risk and severity
- Multi-faceted complications / co-morbidities
- Unpredictable and outcomes from treatment cannot be guaranteed
- Side-effects of some treatments are not insignificant and can often be life-threatening



Impact

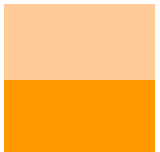
- Shock
- Fear
- Loss
- Out of control
- Relief
- A change for the better (?)
- Life will never be the same again – for the patient and their family



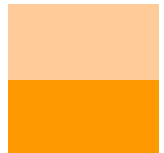
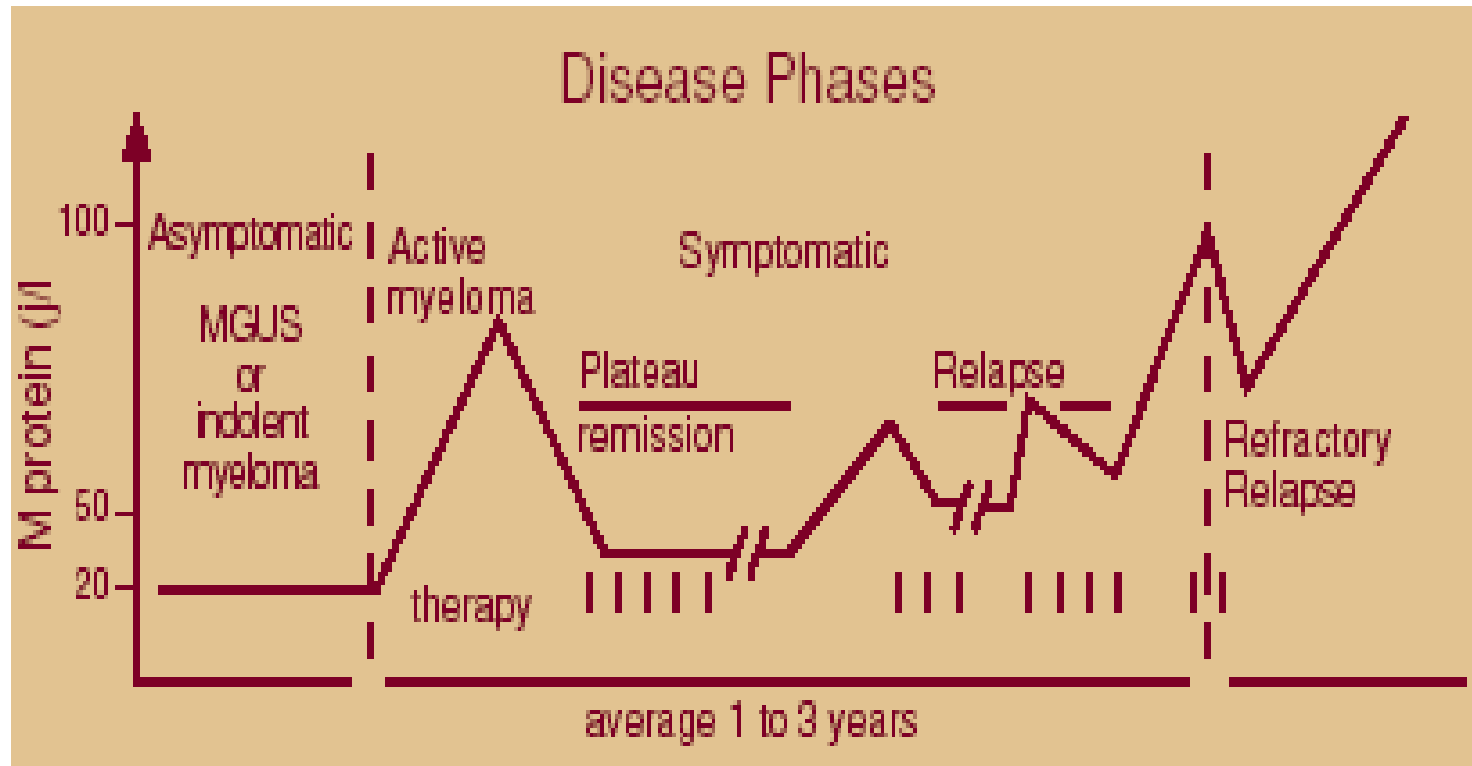
Treatment implications



- Myeloma is not one cancer
- Patients are different – one size does not fit all. Size and fit are likely to change throughout the course of myeloma for a number of possible reasons
- Adjuvant verses palliation verses end of life treatment and care
- Treatment outcomes are not predictable and thought needs to be given to:
 - Risks v benefits
 - Side-effects v efficacy
 - **Acceptable balance for individual patients will be different based on a range of criteria. i.e. diagnosis verses relapse verses end of life**
- Different doctor / patient / NHS perspectives - bisphosphonates
- Treatment options – issues and challenges. Access. Clinical questions still need to be answered



Up until recently outcomes were poor

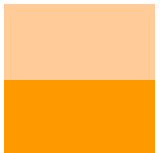
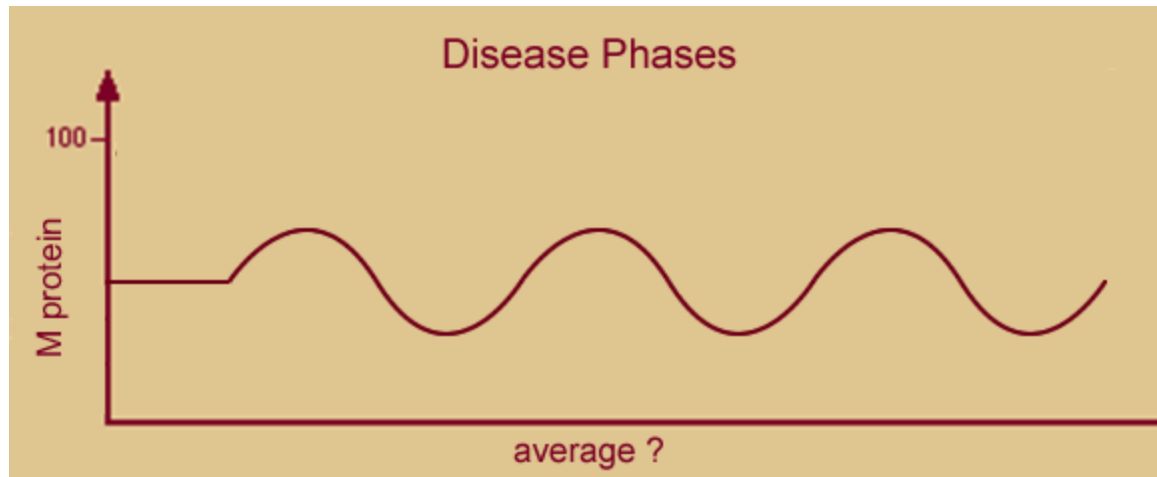


Recent developments

- Minimally effective / optimal dose rather than maximum tolerated
- New effective combinations x 3 / 4 drugs
- Different mechanisms of action of treatment
- Sequencing is key
- Prognostic and predictive medicine
- New trials and combinations
- Better trials and better access strategies
- Implementing / adopting research results
- Improving 5 and 10 year survival (20% still die within 60 days)
- The continued role of MUK and the UKMF



Future myeloma course?



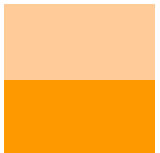
Implications on the setting of care

- Despite these improvements, myeloma remains extremely challenging for both patients and doctors alike
- Its individual nature requires a tailored customised approach which takes account wherever possible of both myeloma-related and individual factors
- It's complex, relapsing and remitting nature requires a degree of expertise to diagnose, treat and monitor
- Patients are required to comply with treatment and be vigilant about side-effects and symptoms etc.
- The current standard of care is mixed and ranges from excellent to un-acceptable – we have the evidence
- It is improving in myeloma due to UKMF / MUK work and collaborations



Addressing the challenge

- HCP education and awareness
- Patient / Family education and awareness
- Improving standards
- Developing an evidence base
- Working with policy etc.
- Improving the standard, delivery and setting of care
- Improving the therapeutic partnership



HCP education and awareness

- The Myeloma Academy© - making excellence easy
 - Hospital doctors
 - Nurses
 - GPs
 - Allied healthcare professionals
- Clinical Guidelines – UKMF / BCSH
- Pass Mark – gold standards framework



Patient / Family education and awareness



- Myeloma Infoline
- Patient and Family Myeloma Infodays
- Patient Experience Exchange Resource Network (PEER)
- Myeloma Support Groups
- Comprehensive printed information
- Comprehensive and interactive website
- Myeloma TV / Myeloma Radio



Improving standards

- Pass Mark© – gold standards framework
- Recognising excellence where it exists
- Providing a framework to improve where improvement is needed
- Designed primarily by patients and the myeloma community



Developing an evidence base

- Health Services Research programme
- Quality of life
- Setting of care
- Treatment perspectives
- Health Economics
- Pricing



Policy

- Responding to consultations
- Position statements
- Engagement with DH teams, MPs (equivalents) etc. in all four nations



Summary

- We need to understand service users more and truly shape services round them.
- Information and support is critical. More CNS / Cancer social workers
- We are caring for people not just a cancer
- Prepare for myeloma as being chronic – with some exceptions
- Myeloma will remain complex and will require expertise
- Get a better balance between efficiency and pragmatism / common sense
- One size does not fit all

