

# **Management of side-effects (social/financial/psychological issues)**

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**Myeloma Patients Europe**

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# Background

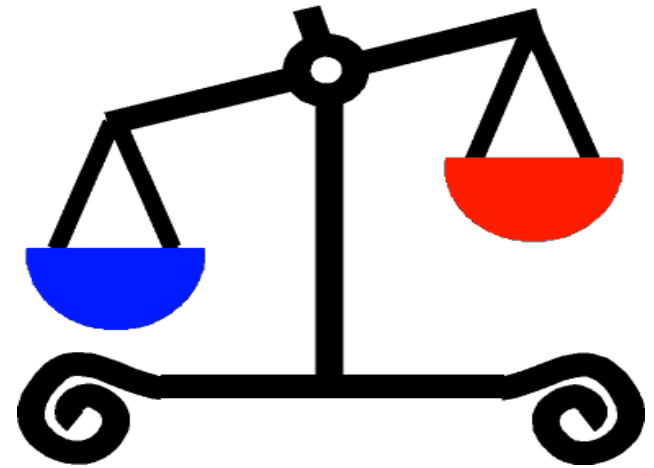
- All treatments have side-effects
- Most are transient and mild
- Some can be permanent and life-threatening
- Side-effects can carry an emotional, social and financial burden




"Listen, when the side effects of this medication kick in, you'll forget what was wrong in the first place!"

# Background

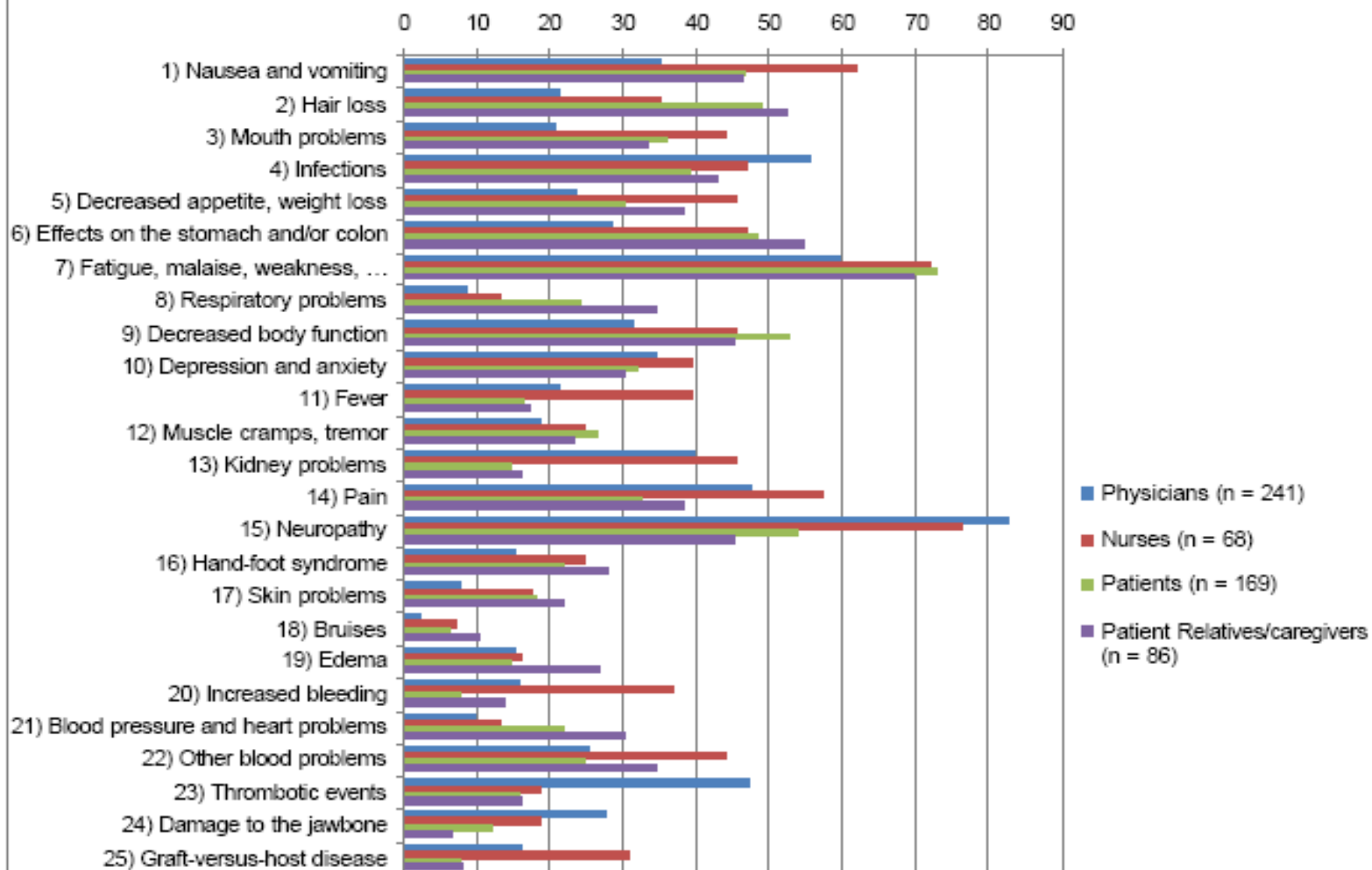
- Perspectives differ between patients on what constitutes an acceptable level of side-effects for any given treatment in relation to the expected or hoped therapeutic outcome
- Perspectives on side-effects may differ between patients and their healthcare team / between patients and their family
- One size does not fit all



# What type of side-effects

- Nausea and vomiting
  - Hair loss
  - Body image changes: skin, weight, hair
  - Emotional: confidence, anxiety etc.
  - Peripheral neuropathy
  - Pain - mucositis
  - Anaemia and fatigue
  - Infection
  - Loss of appetite
  - Loss of libido/sexual function
  - Infertility
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## 5) Treatment side effects with the most negative impact on overall well-being (in %)



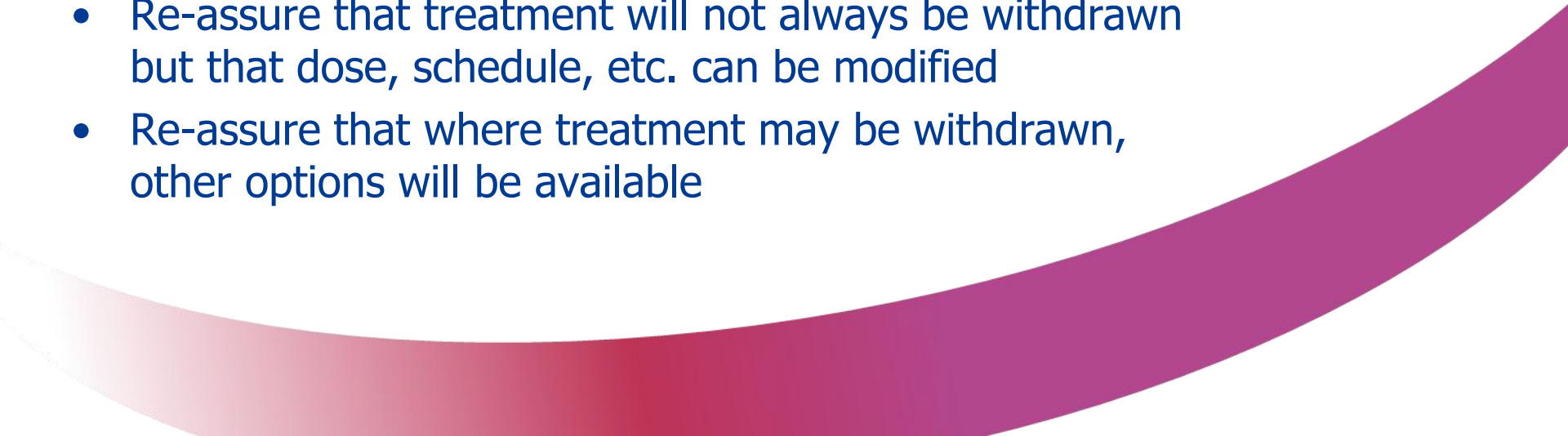
Graph 7)

Myeloma treatment side effects with the most negative impact on overall well-being (in %)


# Consequences of side-effects

- **Emotional:** depression, anxiety, ability to function and think normally, letting the team down
- **Social:** confidence, body image, fatigue and inability to enjoy food or drink alcohol
- **Work:** time of work, inability to carry out job properly, sympathy fatigue from colleagues, reduced working hours, etc.
- **Financial:** inability to work, extra care and treatment costs, impact on family/carers/other household earners
- **Therapeutic benefit of treatment not maximised**

# Side-effect management

- Provide structured and strategic approach to care
  - Ask patients what they want and how they feel about possible side-effects and the impact these may have. If there are better options for individual patients, discuss these
  - Be honest and manage expectations
  - Emphasise the importance of early reporting
  - Give clear guidance on self-vigilance and reporting
  - Re-assure that treatment will not always be withdrawn but that dose, schedule, etc. can be modified
  - Re-assure that where treatment may be withdrawn, other options will be available
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# Side-effect management

- Provide emotional support as a systematic approach to care and offer counselling
  - Recognise and validate patients views on side-effects
  - Promptly refer to supportive/palliative care colleagues for specialist treatment and management
  - Promptly refer to occupational therapy and social work colleagues and provide guidance on speaking to employers
  - Set up a nurse-led clinic
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# Summary

- All treatments have side-effects
- Most are transient and easily managed although some can be permanent
- One size does not fit all and there are often different perspectives between those involved
- Pro-active management to prevent and treat side-effects is critical
- Core part of the 'holistic' management of patients
- Adequate side-effect management will improve patient outcomes and reduce overall healthcare spend



**Thank you!**