

# Living with Myeloma

## A Quick Guide

### Contents

This is a brief summary on 'Living with myeloma' from our website. You will find more detailed information on there.

In this information there are sections on

- Coping with myeloma
- Recovery after intensive treatment for myeloma
- Questions for your doctor
- Myeloma organisations

You can view this information in a larger print on our website.

### Coping with myeloma

It can be very difficult coping with a diagnosis of cancer, both practically and emotionally. You are likely to be feeling very upset and confused. As well as coping with the fear and anxiety that a diagnosis of cancer brings, you have to work out how to manage practically. There may be money matters to sort out. Who do you tell that you have cancer? And how do you find the words? There may be children to consider.

The coping with cancer section of our website contains lots of information you may find helpful. There are sections on:

- Your feelings
- Talking to people: who and what to tell
- Talking to children
- How you can help yourself
- Who else can help you
- Sick pay and benefits and coping financially

### Recovery after intensive treatment for myeloma

It takes a long time to get over intensive treatment such as a stem cell transplant. And it may be several months before you really feel you've got your strength back. You may feel very tired for a long time and may need to build up daily activities gradually. You will need regular follow up appointments after your high dose treatment. These are to check your general recovery and blood cell levels, and find out how well the treatment has worked. Your appointments may be weekly to begin with, but if all is well they will gradually become less frequent.

If possible, your doctor or nurse will remove your central line before you go home. But if you still need platelet or blood transfusions, you will need to keep the tube in until your blood cell levels improve.

### Preventing and avoiding infection

During the first few weeks, you will still be taking a few medicines, mainly to prevent infection. You may need to have some vaccinations, such as a flu jab or a vaccination to prevent chest infections. You may need to avoid certain foods that could contain harmful bacteria and your nurse or dietician will advise you about this. You may also need to avoid crowded places where you could come into contact with people who have infections such as colds or flu.

### Getting back to normal

After some time you will be able to go back to work. It may be helpful to talk to your colleagues beforehand. And to let your employer know if you may need any help at first. Doctors usually advise against going abroad for the first six months. Whenever you go away, it is helpful to carry a doctor's letter outlining your treatment and giving a contact number in case of emergency. You may have difficulty arranging travel insurance. But in the travel section of our website you can find a list of helpful companies.

### Questions for your doctor about living with myeloma

- How will my treatment affect me?
- Will I ever get back to normal, or will I have some long term side effects?
- Will I be able to go back to work?
- Is there anything I shouldn't eat?
- Where can I get help with claiming benefits and grants?
- What practical help is available?
- Why did this happen to me?
- Are my children at risk of getting cancer?
- Where can I get help dealing with my feelings?
- Can you refer me for counselling?
- Do I have to pay for counselling?
- Can I see a specialist nurse?

### Myeloma organisations

#### Cancer Research UK

Website: <http://www.cancerresearchuk.org/about-cancer>  
Cancer Information Nurses phone: 0808 800 4040

#### Myeloma UK

Helpline: 0800 980 3332 (Freephone Mon to Fri, 9.00am to 5.00pm)  
Email: [myelomauk@myeloma.org.uk](mailto:myelomauk@myeloma.org.uk)  
Website: [www.myeloma.org.uk](http://www.myeloma.org.uk)

#### Bloodwise

Telephone: 020 7504 2200  
Email: [info@bloodwise.org.uk](mailto:info@bloodwise.org.uk)  
Website: [www.bloodwise.org.uk](http://www.bloodwise.org.uk)

Bloodwise is the new name for Leukaemia and Lymphoma Research.

## Notes

**For more information**, visit our website <http://www.cruk.org/about-cancer>

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for trials in the UK. Our information is based on the best current scientific evidence and reviewed regularly by leading clinicians and experts in health and social care.

For answers to your questions about cancer call our Cancer Information Nurses on 0808 800 4040 9am till 5pm Monday to Friday.

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