

What happens now?

Information for haematology patients
Finishing treatment

Patients being treated for any haematological condition will experience a variety of treatments in a number of settings.

Who is this leaflet for?

This leaflet is predominantly aimed at patients who have received chemotherapy in a hospital setting over a period of several months either locally or in London where they have undergone a stem cell transplant.

Whilst you have been receiving your chemotherapy you will have been in an environment where you were closely observed by both doctors and nurses.

When your treatment finishes it may feel as though a 'safety net' of support and contact has been removed and you may be left wondering what happens now.

Although the prospect of having finished your treatment is an exciting one, it can also leave you feeling anxious as to what lays ahead.

How will I be followed up?

After chemotherapy you will be seen in the haematology day unit at regular intervals for blood tests, central line care and for review by the nurses. You will also be seen by a haematology consultant in a specialist clinic based in the haematology day unit.

During this time you may need blood and platelet transfusions as well as further tests to see how effective the treatment has been, such as bone marrow biopsies or scans.

If you have had a stem cell transplant your treatment will continue in the day unit up to three times a week depending on the type of transplant you have had.

You will also be encouraged to contact the haematology unit and speak to a member of the specialist team in an emergency if you feel unwell or for any help and advice. You should have been given a 'red card' with emergency contact details and a leaflet with the details of your specialist nurse.

After a period of time, once your intensive follow up has been completed, your central line (if you have one) will be removed and you will be transferred back to the main haematology out patients clinic and may no longer need to see the nurses in the haematology day unit. The length of this period depends upon the treatment you have had.

How will I feel after treatment?

The treatment you have undergone will leave you feeling tired. This is perfectly normal. Concentration and mood can be affected and often people feel as though they do not have enough 'get up and go'.

Tiredness can be both a physical and emotional experience; it is quite normal for tiredness to persist even after treatment has finished and this may last for up to twelve months. This can be frustrating but allowing your body to recover is essential and regular rest is very important. It is also helpful to find the right balance for you and a regular daily routine involving gentle exercise which can also help.

If the fatigue continues to worry you please inform your specialist nurse who may wish to refer you to a physiotherapist.

What about weight loss?

It is probably inevitable that you have lost weight during your treatment. Try to eat regular meals, incorporating foods you enjoy, including foods rich in protein and carbohydrate. You may find that your taste has changed but don't worry, this will gradually return to normal. Some oral medications you may still be taking however can also affect your taste and delay this return to normality.

Information about gaining weight can be obtained through visiting the Macmillan website at www.macmillan.org.uk where you will find a leaflet on this subject. Gaining weight can be a slow process and if you have concerns please mention it to your specialist nurse who will initiate a dietician referral if appropriate.

Should I continue my mouth care regime?

The meticulous mouth care regime you have followed during your treatment may be reduced once your neutrophil count has reached a safe level but feel free to continue if you wish to.

If you need any dental treatment please be sure to mention it to your doctor as you may need treatment before and after the procedure.

What will happen to my hair, skin and nails?

If you lost any hair during treatment it should now start to grow back. Your hair may grow back a slightly different colour and sometimes a different texture. It is best to wait approximately six months before having a perm or colouring your hair. If you need to have your hair coloured avoid using dyes with peroxide or ammonia. Ask your hairdresser to use a natural form of hair colouring.

You may have experienced skin dryness, rashes or discolouration during your treatment. If you are concerned about any new skin rash, contact your specialist nurse for advice. Your skin may take some time to return to normal and it is a good idea to continue to use plenty of unperfumed moisturising lotion. Most chemotherapy drugs can increase the sensitivity of your skin. Take care in the sun; avoid the midday sun; protect your skin with a high factor sun cream, or cover up; avoid sunbathing.

If you have experienced any changes to your nails such as thickening, discolouration and ridging, they should now start to slowly recover.

If you have experienced any changes in sensation to your feet or hands such as tingling or numbness this will usually lessen as the months go by. However, occasionally these changes may be permanent.

Fertility and contraception

As explained at the beginning of your treatment, it is very likely that the chemotherapy treatment has temporarily or permanently caused you to become infertile; but without a long series of tests, it is impossible to know for certain. Even if you or your partner are considering having a baby, it is very important you do not try to do so immediately, so you must continue to use some form of contraception.

If you are thinking of starting or adding to your family, please discuss it with your consultant. It is usually advisable that you wait a minimum of two years.

For Women under 40 who before treatment had regular periods, your cycle should return to normal within a few months. If however, you were approaching the menopause before treatment, it is very likely that your periods will not resume and menopausal symptoms may be experienced.

This leaflet is designed to give you general advice. If you have any specific queries at this final stage of your treatment, please contact your specialist nurse.

Summary of treatment

Diagnosis date: _____

Diagnosis: _____

Treatment: _____

Bone Marrow Biopsy

Results: _____

Scan

Results: _____

Specialist Nurse: _____

Consultant: _____

Contact details: _____

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Disclaimer

The information in this leaflet is for guidance purposes only and is in no way intended to replace professional clinical advice by a qualified practitioner.

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