



# Going home after inpatient chemotherapy

## Information for haematology patients

**This information leaflet aims to help answer some questions you might have about returning to your everyday activities after chemotherapy. If you have any further questions, please contact your clinical nurse specialist (CNS).**

### When can I leave hospital?

This varies from patient to patient so your medical team will discuss this with you. Usually, you can leave hospital when you have finished your chemotherapy treatment. In some cases (for example after the first chemotherapy course for acute leukaemia) you will need to stay in hospital until your white cells (neutrophils) have recovered enough to fight infections again.

### After leaving hospital

**After chemotherapy treatment you are at higher risk of developing an infection. To help lower this risk you will need to:**

- Try to avoid crowded places, such as public transport in busy periods, school playgrounds, pubs and shopping centres.
- Stay away from people who are unwell or have been in contact with infectious diseases, such as chicken pox.
- Maintain a high standard of personal cleanliness (daily showers/baths) and make time to keep your teeth, gums and mouth clean.
- Always wash your hands thoroughly after contact with pets and try not to have close facial contact with them.
- Take care when gardening – wear gloves to avoid cuts. Make sure you wash your hands as needed and when you are finished – the fungus and spores that live in the ground can be harmful to your weakened immune system.

### Looking after your Hickman or PICC line

You may have a Hickman or PICC line in place. The dressing and bungs (caps) should be changed twice a week while you are in hospital and weekly when you are at home. You will need an appointment in the haematology day unit for this.

While you are at home, look at the exit site of your line every day for redness, soreness or any oozing. Please call the hospital if you have any of these symptoms. Check that the bungs on your line are secure and that the clamp is closed each day.

## **Will I be in pain?**

You might feel some discomfort after your Hickman or PICC line has been put in. Many people find that taking a mild painkiller helps to ease this. This pain should pass a few days after your line has been put in. If the pain does not go away, please contact the hospital.

You may develop sores in your mouth due to the chemotherapy, which can be painful. If this happens, please tell the doctor or nurse looking after you.

## **Do I need to change my diet?**

It is important that you eat food from reputable manufacturers only and make sure that all food is within its use-by date. Good hand washing is important at all times, but especially when handling food. Make sure all food is correctly prepared and thoroughly cooked. Avoid take-a-ways as there is no guarantee that this food is freshly prepared.

If you are struggling with eating and drinking, have lost weight, or would like to see the haematology dietician, please contact your CNS.

## **When can I return to normal activities?**

Your doctor will talk to you about when you can go back to work. This is normally after all your chemotherapy is finished. You will feel fatigued (extremely tired) after chemotherapy so doing household chores may be difficult. You should take things slowly and not expect too much too soon. There are various methods of coping with fatigue – please speak to your CNS about these.

It is likely that chemotherapy could affect your sex life. You may feel too tired or experience reduced desire for sexual activity. This is common and likely to return to normal with time. We would, however, advise not to have sexual intercourse while your blood counts remain low because of increased risk of infection. If you would like to have a one-to-one chat about this, please speak to your CNS or your doctor.

If you or your partner is of child-bearing age, we recommend that you use a reliable method of contraception for at least the first year after treatment. Exposure of chemotherapy to your partner (via bodily fluids) can be dangerous, and is toxic to a foetus. Infertility is common after treatment for haematological cancers but there may still be a small possibility of becoming pregnant. Some women may also need to be referred for hormone replacement therapy (HRT). Again, this will depend on the type of chemotherapy you have had.

## **Will I have a follow-up appointment?**

You will have regular follow-up appointments in the Haematology Day Unit and the Haematology Outpatients Clinic until your blood count has recovered fully. This is because you may need blood product support, such as platelets or a blood transfusion. If needed, this will be arranged for you before you leave hospital.

## **What should I do if I have a problem at home?**

Please make sure you have a thermometer before you go home. A high temperature (over 38°C) or a low temperature (below 35°C) could be a sign of infection which your immune system may be unable to fight. Any infection must be treated quickly with antibiotics so please be prepared to be admitted to hospital for immediate antibiotic treatment.

**Please follow the guidance below, but if in doubt, please contact the hospital:**

- If your temperature is 37.5°C, repeat in one hour. If your temperature has increased, whether you feel unwell or not, you must contact the hospital.
- If you have a temperature of 38°C or above, whether you feel unwell or not, you must contact the hospital immediately. **Please do not wait any amount of time before you call us.**
- If you feel unwell but do not have a temperature, monitor your temperature every one to two hours. If you continue to feel unwell, please contact the hospital.
- If you wake up in the middle of the night with a high temperature, **contact the hospital immediately – do not wait until morning.**
- If you feel cold and shivery, even if you do not have a high temperature, please contact the hospital.
- If you have more than two episodes of vomiting or diarrhoea, or you are concerned, please contact the hospital as you may become dehydrated quickly.
- If you start to cough up phlegm, have any shortness of breath or chest pain when breathing in, please contact the hospital.
- Look for signs of bleeding, such as bruising, bleeding gums, nose bleeds, coughing up blood, or passing blood in your urine or stool. This may be due to a low platelet count. Please call the hospital if you notice any of these signs.
- If you develop a rash, headache, stomach pain or any weakness, please call the hospital.

**There is always a doctor or nurse available 24 hours a day if you need help.**

## **Useful sources of information**

### **BloodWise**

**t:** 0808 2080 888

**w:** [www.bloodwise.org.uk](http://www.bloodwise.org.uk)

### **Cancer Research UK**

**t:** 0808 800 4040 (freephone)

**w:** [www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)

### **Macmillan Cancer Support (freephone)**

**t:** 0808 808 00 00

**w:** [www.macmillan.org.uk](http://www.macmillan.org.uk)

## Contact us

### Acute Oncology Service

The Acute Oncology Service (AOS) enables cancer patients to access advice, assessment and treatment in an appropriate timeframe. The service is available to be accessed directly by patients with a known cancer diagnosis who are receiving or have received treatment at Guy's and St Thomas'. **t:** 020 7188 3754 (Monday to Friday, 8.30am to 6.30pm)

**Karen Stanley** – clinical nurse specialist in haematology (lymphoma)  
**t:** 020 7188 9333 (CNS Helpline)

**Nicola Shepherd** – clinical nurse specialist in haematology (leukaemia)  
**t:** 020 7188 9333 (CNS Helpline)

**Grace Milner** – clinical nurse specialist in haematology (myeloma)  
**t:** 020 7188 9333 (CNS Helpline)

### Haematology Day Unit

**t:** 020 7188 2745 (Monday to Friday, 9am to 5pm)

### Cancer (Chemotherapy) Day Unit

**t:** 020 7188 6452 (Monday to Friday, 9am to 5pm)

### Out of hours

The haematology registrar (a senior doctor) can be contacted outside of normal working hours (evenings, weekends and bank holidays) by calling the hospital switchboard on 020 7188 7188. Say 'operator' and then ask to speak to the haematology registrar.

Guy's and St Thomas' hospitals offer a range of cancer-related information leaflets for patients and carers, available at [www.guysandstthomas.nhs.uk/cancer-leaflets](http://www.guysandstthomas.nhs.uk/cancer-leaflets). For information leaflets on other conditions, procedures, treatments and services offered at our hospitals, please visit [www.guysandstthomas.nhs.uk/leaflets](http://www.guysandstthomas.nhs.uk/leaflets)



**Dimbleby Cancer Care** provides cancer support services for Guy's and St Thomas'. We have a drop-in information area staffed by specialist nurses and offer complementary therapies, psychological support and benefits advice for patients and carers.

Dimbleby Cancer Care is located in the Welcome Village of the Cancer Centre at Guy's. **t:** 020 7188 5918 **e:** [DimblebyCancerCare@gstt.nhs.uk](mailto:DimblebyCancerCare@gstt.nhs.uk)

## Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the clinical nurse specialist or other member of staff caring for you or call our helpline.

**t:** 020 7188 8748 9am to 5pm, Monday to Friday

## Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

**t:** 020 7188 8801 (PALS) **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

**t:** 020 7188 3514 (complaints) **e:** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

## Language and Accessible Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch:

**t:** 020 7188 8815 **e:** [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

## NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

**t:** 111

## NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

**w:** [www.nhs.uk](http://www.nhs.uk)

## Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

**t:** 0800 731 0319 **e:** [members@gstt.nhs.uk](mailto:members@gstt.nhs.uk)

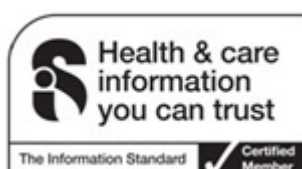
**w:** [www.guysandstthomas.nhs.uk/membership](http://www.guysandstthomas.nhs.uk/membership)

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