



# Haemato-oncology patient information

## Information for patients with

- lymphoma
- myeloma/plasma cell disorders
- myeloid syndromes (leukaemia/MDS)
- chronic lymphocytic leukaemia (CLL)
- myeloproliferative neoplasm

Welcome to Guy's and St Thomas' Hospitals. Your doctor has made a referral for you to see the haemato-oncology team at Guy's and St Thomas' Hospitals. This leaflet will give you some information about the team and the services available.

The team is made up of consultants and their colleagues who specialise in the treatment of patients with these conditions. If you are ever unsure about who is in charge of your care, please ask a member of staff.

## Your key worker

You will be given the name of your key worker at your clinic appointment and they will help you with any questions about your care. Your key worker is usually a nurse specialist, who has experience of looking after patients with your condition.

**Your key worker is** .....

Contact numbers for the haemato-oncology, including out of hours details, can be found on pages 3 and 4 of this booklet.

If your treatment has to be transferred to another hospital, your key worker may change. We will make sure that you are kept informed if this happens.



## Your appointments

Appointments will take place at:

Guy's Cancer Centre, Guy's Hospital, Great Maze Pond, London SE1 9RT

**Myeloproliferative neoplasm (MPN) patients**, will have their appointments at:

Haematology 2 Outpatient Clinic, 4th floor, Southwark Wing, Guy's Hospital.

Clinic clerk and contact number for MPN patients: **t:** 020 7188 1448,

**e:** haematologyappointments@gstt.nhs.uk

For all other specialities as listed in this booklet:

**Cancer Centre clinic appointments and reception**, **t:** 020 7188 7188

**Haematology Department**, **t:** 020 7188 2756

**Chemotherapy appointments team**, **t:** 020 7188 8045 or 020 7188 3755

Your appointment details will either be on your appointment card, confirmed by letter, or a text message will be sent to your mobile. If it is not clear, please telephone the appropriate team as above.

We will try not to keep you waiting in the clinic, but delays can sometimes happen. You may like to bring something to read to pass the time. You are also very welcome to bring refreshments with you.

You may decide that you want to have another person with you during your appointment. This could be a relative or friend who can help you to remember the information given to you by the doctor. If you have any questions, it may be helpful to write them down and bring them with you.

So that we have correct details about you, please bring with you a list of any tablets that you are taking.

After every outpatient appointment, your doctor will write to your GP to keep them informed of your care. Please ask the doctor, nurse or GP if you would like a copy of this. Please make sure the details we have for you are correct, for example, your GP, home address and your telephone number(s).

Guy's and St Thomas' is a teaching hospital where medical and nursing students come to learn. The doctor will ask you if students can be present during your appointment. If you do not want students at your appointment, please let us know. Your wishes will always be respected and your care will not be affected in any way.

We are always trying to develop the treatment of your condition and your consultant may invite you to be part of a study or clinical trial. Your consultant will give you full details about a trial if they think it is appropriate for you. There will be plenty of time to discuss this further with your doctors. If you would like more information, Macmillan produces a free booklet about clinical trials (see page 5 for their contact details).

## How to contact us

Contact details for members of the haemato-oncology team are on the following pages. Please contact us if you have any questions or need advice.

If you do not know which member of staff you should call, the clinical nurse specialists (CNS) may be able to help you. You can contact them using the dedicated CNS helpline. The line is open Monday to Friday, 8.30am-5.30pm. A message will be taken and you will be informed of a specified time frame when a haemato-oncology CNS will call you back.

Finally, if at any time you feel you have not had enough information, or that we are not meeting your needs, please let us know.

## Useful Contacts details:

Who?	What for?	How to contact
Outpatient appointment coordinators	To book, change or cancel outpatient appointments.	<b>t:</b> 020 7188 8045 or 020 7188 3755
For myeloproliferative neoplasm (MPN) patients <b>only</b>	To book, change or cancel outpatient appointments.	<b>t:</b> 020 7188 1448 <b>e:</b> haematologyappointments@gstt.nhs.uk
Acute oncology service (AOS)	For over-the-phone advice if you feel unwell.	<b>t:</b> 020 7188 3754 (24-hour, 7-days-a week helpline) For patients on chemotherapy/radiotherapy <b>only</b>
Haematology Day Unit (HDU)	For supportive medication and routine blood test.	<b>t:</b> 020 7188 2743
Hospital transport assessment/ Transport request	To book hospital transport to and from your appointments.	<b>t:</b> 020 7188 2888
Chemotherapy Village	For chemotherapy bookings and queries.	<b>t:</b> 020 7188 6452 <b>e:</b> chemoenquiries@gstt.nhs.uk
Radiotherapy at Guy's	Treatment support office.	<b>t:</b> 020 7188 4220 Monday to Friday, 8.30am-5.30pm with answer phone
Radiotherapy bookings at Guy's	For all radiotherapy-related booking queries.	<b>t:</b> 020 7188 3160
Dimbleby Cancer Care	Providing cancer support services.	<b>t:</b> 020 7188 5918 <b>e:</b> DimblebyCancerCare@gstt.nhs.uk

## Members of the haemato-oncology clinical nurse specialist team

**Please note all CNSs can be contacted via the CNS helpline on:**

**t:** 020 7188 9333 (CNS Helpline), Monday to Friday, 9am-5pm

### **Chronic lymphocytic leukaemia (CLL)**

Julia Dahlstrom, **e:** julia.dahlstrom@gstt.nhs.uk

### **Lymphoma**

Julia Dahlstrom, **e:** julia.dahlstrom@gstt.nhs.uk

Nicola Shepherd, **e:** nicola.shepherd@gstt.nhs.uk

Karen Stanley (advanced nurse practitioner), **e:** karen.stanley@gstt.nhs.uk

### **Myeloid syndromes (leukaemia/MDS)**

Laura Barr, **e:** laura.barr@gstt.nhs.uk

### **Myeloma/Plasma cell disorders**

Grace Milner, **e:** grace.milner@gstt.nhs.uk

Rosemarie Bone **e:** rosemarie.bone@gstt.nhs.uk

### **Myeloproliferative neoplasm (MPN)**

Claire Woodley **e:** claire.woodley@gstt.nhs.uk

### **Other members and departments**

Acute oncology service, **t:** 020 7188 3754

Cancer (chemotherapy) day unit, **t:** 020 7188 6452

Haematology day unit, **t:** 020 7188 2743

Haematology dietitian **t:** 020 7188 4128 or 020 7188 7188, **bleep** 1829

Occupational therapist, **t:** 020 7188 4185

Physiotherapist, **t:** 020 7188 7188, **bleep** 2557 or 2418

Treatment support radiographers, **t:** 020 7188 4220

## **Acute oncology service**

The acute oncology service (AOS) enables cancer patients to access advice, assessment and treatment in an appropriate time frame. **t:** 020 7188 3754 (24-hours/7-days-a-week helpline).

The service can be accessed directly by patients with a known cancer diagnosis who are receiving or have received chemotherapy/radiotherapy at Guy's and St Thomas'.

### **Please contact the AOS if you:**

- are feeling unwell
- have a temperature over 37.5C
- have any other symptoms you are concerned about/unsure of.

## **Inpatient care**

There are two cancer wards on the Guy's site. If you need to be admitted into hospital, your doctors will try to get a bed for you on one of these wards.

### **Samaritan Ward**

8th Floor, Borough Wing, Guy's Hospital

**t:** 020 7188 8855

### **Hedley Atkins Ward**

8th Floor, Borough Wing, Guy's Hospital

**t:** 020 7188 8854

## Going home after chemotherapy

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

- 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.

## 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-aways 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 dietitian, 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 you 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 doctor.

If you or your partner is of child-bearing age, we recommend that you use a reliable method of contraception for at least a year after treatment. Exposure of chemotherapy to your partner (through bodily fluids) can be dangerous, and is toxic to a foetus. Infertility can occur after some treatment for haematological cancers, but there may still be a possibility of becoming pregnant. Some women may also need to be referred for hormone replacement therapy (HRT), but 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 Outpatients Clinic before your next cycle of chemotherapy. You may need to be seen in our Haematology Day Unit for a blood test in between treatments – your doctor or CNS will tell you if you need to do this.

## Additional support

There are a number of health professionals in the team who may also be able to help you. These include specialist nurses, radiographers, dietitians, physiotherapists, occupational therapists, counsellors, psychologists, carers' counsellors, complementary therapists, and the chaplain. Please let us know if you would like to contact any of these health professionals.

If you need additional help at home, please talk to the doctors or nurses who may be able to arrange social services or home nursing support.

## After treatment

After your course of treatment, you will be offered an end-of-treatment appointment with your CNS. This will give you an opportunity to discuss early and late side effects of treatment, lifestyle advice and disease monitoring, which we hope will help you to look forward to the future. You will then be seen regularly by the doctors and/or nurses to monitor your progress.

## Further sources of information

Please contact your CNS about support groups run at GSTT or in your area

**Bloodcancer**, **t:** 0808 169 5155, **w:** [www.bloodcancer.org.uk](http://www.bloodcancer.org.uk)

**Cancer Research UK**, **t:** 0808 800 4040 (freephone), **w:** [www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)

**CLL Support Association**, **t:** 0800 977 4396, **w:** [www.clisupport.org.uk](http://www.clisupport.org.uk)

**Lymphoma Action**, **t:** 0808 808 5555 (Freephone), **w:** [www.lymphoma-action.org.uk](http://www.lymphoma-action.org.uk)

**Leukaemia Care**, **t:** 0800 169 6680, **w:** [www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)

**Macmillan Cancer Support**, **t:** 0808 808 0000 (freephone), **w:** [www.macmillan.org.uk](http://www.macmillan.org.uk)

**MPN Voice**, **t:** 07934 689354, Monday to Friday, 8am-5pm, **w:** [www.mpnvoice.org.uk](http://www.mpnvoice.org.uk)  
**e:** [info@mpnvoice.org.uk](mailto:info@mpnvoice.org.uk)

**Myeloma UK**, **t:** 0800 980 3332, **w:** [www.myeloma.org.uk](http://www.myeloma.org.uk)

**Trekstock**, **t:** 020 7388 1200, [www.trekstock.com](http://www.trekstock.com), Twitter: @trekstock  
(Young adult cancer support: for any one diagnosed with cancer in their 20s and 30s)

### Contact us

Your haemato-oncology team are available from Monday to Friday, 9am-5pm. For out of hour's advice (not for appointment queries), please contact the AOS (see page 5 for telephone number).

Guy's and St Thomas's hospitals offer a range of cancer-related information leaflets for patients and carers, available at **w:** [www.guysandstthomas.nhs.uk/cancer-leaflets](http://www.guysandstthomas.nhs.uk/cancer-leaflets).

**Dimbleby  
Cancer  
Care**

**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)

**Leaflet number: 1004/VER9**

Date published: July 2020

Review date: July 2023

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A list of sources is available on request

**NHS**

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NHS Foundation Trust