Information for
Chemotherapy Patients

Exceptional healthcare, personally delivered
What to expect

Where will it be given?

- If you are having oral chemotherapy you will be seen in the Haematology Outpatients Clinic by a Doctor or Clinical Nurse Specialist (CNS). You will always be given enough medication to last until your next clinic appointment.
  - Your first cycle of treatment will be given to you in the chemotherapy clinic by the specialist nurse or consultant pharmacist. This takes place at Gate 5 in the Brunel Building, Southmead Hospital on a Monday afternoon. Here you will have the opportunity to discuss your treatment and any questions you have about taking it.
- If your chemotherapy is intravenous or subcutaneous you will attend the Chemotherapy Suite in Medical Day Care, Brunel Building, Southmead Hospital for your treatment.

What do I need to bring with me to the Chemotherapy Suite?

- Drinks and snacks are provided throughout the day and a lunchtime sandwich but feel free to bring your own refreshments.
- We have portable DVD players and DVDs which you can borrow and some magazines and books, or you can bring your own laptop, DVD player, kindle etc. Wi-fi internet access is available.
- Some patients like to have a family member or friend with them during their treatment; this is entirely up to you.

Will it hurt?

The chemotherapy treatment should not be painful. If you are feeling pain let a member of staff know immediately.
Pre-Assessment

Before starting each cycle of chemotherapy you will be seen by a Doctor or senior nurse. You will also be asked to give a blood sample and have your blood pressure and temperature checked. This is a good opportunity to discuss any problems or side effects you are concerned about.

The pre-assessment will help to decide whether you are fit enough to start the next chemotherapy treatment and whether any adjustments are needed.

Side effects

Side effects vary depending on the type of treatment you are receiving. You will be given specific information about the side effects you might experience.

Infection (sepsis)

Your disease and the chemotherapy treatment can make you more vulnerable to infection. Neutrophils are white blood cells that fight off infections and if they are low then you are much more vulnerable to catching infections and becoming unwell. Your neutrophil count is a good indicator as to how vulnerable you are.

A normal neutrophil count is between 1.8 and 8.0 x 10^9/L. Usually the neutrophil count drops approximately 7-10 days after having chemotherapy (we call this neutropenia). It is safe to be at home with a low count as long as you do not have any symptoms of infection but it is a good idea to be extra careful, avoiding people with coughs, colds and infections as well as large gatherings of people for example the cinema, theatre and restaurants. Hand-washing for example: before and after going to the bathroom, handling food or rubbish and before eating is probably the most important thing you can do to avoid picking up infections.

We will take extra precautions if you are in hospital whilst your count is less than 1.0 x 10^9/L.
Neutropenic sepsis is a life-threatening emergency: Call for help immediately if you have recently had chemotherapy or if you have been told that your condition puts you at risk and you become unwell with any of the following symptoms:

- Temperature – Above 38°C
- Uncontrollable shivering/shaking (rigor)
- Other signs of infection e.g. Sore throat, cough, diarrhoea, pain or difficulty passing urine
- Suddenly feeling unwell, even with a normal temperature

Use the numbers on your Chemo-Alert card to speak to a nurse straight away. Depending on the reason for calling you may be asked to attend your GP or to come to a specific department in the hospital.

If there is a delay in contacting us or you are not happy with the advice you have been given please go straight to the nearest emergency department (you may have to dial 999 for an ambulance if you do not have access to suitable transport).

Do not attempt to come to the haematology department or chemotherapy suite without a prior arrangement as it will not always be possible for you to be seen by a doctor and this may lead to a delay in getting the attention you need.

If you are admitted to hospital with a possible infection you need to receive an intravenous dose of antibiotics within one hour of arriving. Please show your Chemo-Alert card to staff and make sure they are aware of this target.

Nausea and Vomiting

Not all chemotherapy causes nausea and vomiting. If your chemotherapy is expected to cause nausea, we will give you anti-sickness medication. This may include tablets to be taken regularly or as needed. We will explain the best way to take them. If you are unsure how to use them or if they are not controlling your symptoms please contact us.
**Hair Loss**

Not all chemotherapy causes hair loss. Your CNS or chemotherapy nurse will be able to advise you about this. If you would like to be referred for a wig they are able to organise this for you. If hair is lost during chemotherapy it invariably grows back after treatment has finished but can be different in colour or texture than before.

**Psychological Issues**

A diagnosis of cancer can cause many different feelings and emotions. People react in different ways and there is no right or wrong way to feel.

If you are feeling overwhelmed and/or distressed, please feel free to speak to any of the Haematology team about your concerns.

**Chemotherapy and your daily routine**

**Driving**

You do not have to inform the DVLA that you are undergoing chemotherapy. We recommend that you do NOT drive to your first chemotherapy session as it is difficult to know how you may be affected by the drugs given. For example, some pre medication can make you feel drowsy. If you are feeling at all unsafe then do not drive. In some cases we can offer hospital transport for your journeys to and from hospital.

If you are undergoing chemotherapy within North Bristol NHS Trust you are entitled to a free car parking pass. This is valid for up to 3 months and is renewable for as long as you need it. Please ask the CNS or chemotherapy staff for details.

**Work**

It is entirely up to you whether you continue to work or not throughout the course of chemotherapy treatment. Please discuss this with your consultant. They will be able to advise you depending on your occupation and the environment in which you work. We have specific detailed information with regards to issues surrounding employment and your rights, please ask your nurse for more details.
**Going on holiday**

We recommend that you do not travel abroad during chemotherapy treatment. Your doctor can advise you about having a holiday within the UK. If your blood counts are satisfactory and you feel well, you may benefit from a short break within the UK. It is important that your life is not completely put on hold during this difficult time. **If you become unwell when you are away from home do not attempt to return to Bristol before seeking help. Please go to the nearest hospital with an emergency department.** Take your chemotherapy alert card with you and provide as much information as you can about your diagnosis and the treatment you are having.

**Exercise**

Exercise can mean a variety of things to different people. Research has shown that some gentle exercise has been beneficial to patients undergoing chemotherapy. However, this does depend on how you feel. It is important that you do not push yourself too much. If you feel tired or fatigued, it is important to rest. However sometimes getting out for some fresh air or to walk the dog can be just as beneficial.

**Financial Issues**

We know that living with cancer can have a significant impact on your income and the cost of living. There is a team of benefits advisors provided by Macmillan and the Citizens Advice Bureau. Talk to your CNS or the team at the Macmillan Wellbeing Centre and ask to be referred.

If there is a specific item that you need and would make your life easier during your cancer treatment you can apply for a **Macmillan Grant**. This is means tested and involves completing a form detailing your income and what you would like the money for. Examples of items for grants include a tumble dryer to make washing clothes easier or new clothes following a dramatic weight loss linked to disease. Ask your CNS or Chemotherapy Nurse for further details.

If you have a cancer diagnosis you are entitled to **free NHS prescriptions**. If you do not already have exemption from prescription charges please ask the CNS about this.
Clinical Nurse Specialist (CNS)

Everybody with a cancer diagnosis has access to a specialist nurse or Macmillan nurse.

The role of this nurse is to provide you and your family with the support and information you and your family need before, during and after your treatment.

You should see the CNS before you start your treatment. Whenever possible this will happen in the outpatient clinic or Medical Day Unit at the same time as another appointment, however you may be invited to come at a different time if this is not possible.

For most chemotherapy patients the CNS will be your ‘Key Worker’ and your point of contact with the Multi-Disciplinary Team responsible for your care.

Our CNSs are Lucy Henderson and Graeme Butters. They work Monday to Friday from 8am to 5pm and can be contacted by phone or email. Please be prepared to leave a message as they may not be able to answer straight away.

Tel: 07545 421893

Email: haematologyCNS@nbt.nhs.uk

Acute Oncology Nurses

The Acute Oncology Nurses work Monday to Friday 8am to 4.30pm and are contactable on 07860 783116.

The Acute Oncology Service provides specialist advice and support for cancer patients when they have urgent problems related to their illness or treatment. They work closely with the Haematology team and other services in the hospital to ensure urgent problems are managed safely and effectively. They will endeavour to respond to your call as quickly as possible and should be the first port of call if you are unwell.

They will be able to advise the most appropriate course of action whether this is to attend hospital or your GP for assessment.
NGS Macmillan Wellbeing Centre

The Wellbeing Centre is located opposite the main hospital entrance at the end of the car park, next to the Breast Care Centre. They provide a wealth of additional support for patients and their families, including: information, financial, psychological and dietary advice and complementary therapies. There is always free tea and cake and the chance to talk to someone in a confidential, non-clinical environment.

You can drop in Monday- Friday 9.30am-4.30pm or call 01174147051

Other Sources of Information

Bloodwise
Provides information on blood cancers and disorders including leukaemia, Hodgkin’s and other lymphomas and myeloma.
https://bloodwise.org.uk/
Tel: 020 7504 2200

The Lymphoma Association
Provides emotional support and information on a range of issues to anyone with lymphatic cancer, their families, carers and friends.
www.lymphomas.org.uk
Helpline: 0808 808 5555

Cancer Research UK
Information service about cancer and cancer care for people with cancer and their families.
www.cancerresearchuk.org
Tel: 0808 800 4040
Myeloma UK
Information and support for all those affected by myeloma and aims to improve treatment and care through education, research, campaigning and awareness. Also information on related disorders including AL amyloidosis, Monoclonal Gammopathy of Undetermined Significance (MGUS), Plasmacytoma, Waldenström’s macroglobulinaemia.
www.myeloma.org.uk
Myeloma Info line: 0800 980 3332

Macmillan Cancer Support
Offers a range of support for the emotional and practical impacts of living with cancer.
www.macmillan.org.uk
Ask Macmillan: 0808 808 0000

NHS Choices
Offers general health information
http://www.nhs.uk
NHS Choices: 111

Myelodysplasia Patient Support
Offers information and up to date developments in this field.
www.mdspatientsupport.org.uk/
Telephone: 020 7733 7558

MPD Voice
Offers information and support to patients with a myeloproliferative disorder
www.mpdvoice.org.uk

Details of support groups and websites correct at time of printing, September 2016.
List of Resources/Publications available in the Medical Day Unit

Understanding Non-Hodgkin’s Lymphoma
Understanding Hodgkin’s Lymphoma
Understanding Chronic Lymphocytic Leukaemia
Understanding Chronic Myeloid Leukaemia
Understanding Acute Myeloid Leukaemia
Understanding Myeloma

Understanding Chemotherapy
Understanding Radiotherapy
Coping with Hair Loss
Coping with Fatigue
Diet and Cancer
Recipes from MacMillan Cancer Support
Work and Cancer
Working while caring for someone with cancer
Sexuality and cancer
Cancer treatment and fertility: information for women
Cancer treatment and fertility: information for men
Sperm freezing for cancer patients
Getting travel insurance when you have been affected by cancer
**URGENT PROBLEMS**
May include:
- Temperature 38°C or more.
- Suddenly feeling unwell after chemo.
- Severe pain.
- Nausea or vomiting which does not get better with the tablets you have been given.

Is the patient conscious and breathing normally?

- No
  - Dial 999 immediately and ask for an ambulance

- Yes
  - Is it Mon-Fri 8am-4.30pm?
    - Yes
      - Call the Acute Oncology Team on: 07860 783116
    - No
      - Call the Clinical Hub on: 0117 4140700. Be sure to mention that you are at risk of neutropenic sepsis.

**MINOR SYMPTOMS**
which can wait till the next working day

- Mon-Fri 8am-5pm:
  - Call Haematology CNS: 07545421893
  - If we are unable to answer please leave a message and we will call you back
  - or
  - Mon-Fri 8am-4pm:
    - Call the Acute Oncology Team: 07860 783116
  - Call or text
    - Haematology CNS: 075454218793
  - Or email:
    - haematologyCNS@nbt.nhs.uk

**GENERAL QUERIES**
(Non-urgent)

- In the unlikely event that you are unable to contact us please dial 999 or go to the nearest emergency department. Take your Chemo-Alert card with you and present it to staff on arrival.
If you or the individual you are caring for need support reading this leaflet please ask a member of staff for advice.

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