



Lynda Jackson Macmillan Centre

support & information at Mount Vernon Cancer Centre
... supporting people affected by cancer...

This leaflet forms part of a series of publications produced by the Lynda Jackson Macmillan Centre (LJMC).

If you would like further information about any aspect of cancer and its treatments, please drop in to the centre or call the Helpline.

The LJMC is staffed by healthcare professionals and trained volunteers and is part of the Mount Vernon Cancer Centre.

Services offered at the LJMC include:

- Drop-in centre for support and information
- Telephone helpline
- Benefits advice*
- Complementary therapies*
- Relaxation classes
- Counselling*
- Look Good...Feel Better™ beauty workshops
- Self-help courses

* These services are available to NHS patients under the care of an oncologist based at Mount Vernon Cancer Centre.



The **Lynda Jackson Macmillan Centre** is situated between the Cancer Centre and Gate 3 (White Hill)

Opening hours: **Mon-Fri: 9.30am-4.30pm**

Mount Vernon Cancer Centre, Northwood, Middlesex HA6 2RN
Telephone Helpline: **020 3826 2555**
Website: www.ljmc.org



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a patient's guide

Chemotherapy

Patient Information Series PI 02



East and North Hertfordshire
NHS Trust



Mount Vernon
Cancer Centre



The chemotherapy you will receive is called:

You may be given a specific information sheet about these drugs; if not, please ask if one is available.

Consent

It is a legal requirement to have a signed consent form from you before the start of your treatment.

If you have already been given one of these forms, please bring the completed form with you when you come for your first appointment.

If you have not been given a form, this will be discussed with you at your appointment.

Identification

Please note that it is a legal requirement for the staff to check your name and details against your treatment sheet and your hospital name band each time you attend.

You must wear your name band at all times whilst in hospital.

This leaflet has been produced by professionals, patients and carers from Mount Vernon Cancer Centre who have expertise and experience in the topics covered by this publication. All our publications are reviewed and updated regularly. Details of the references used to write this information are available from the Information Team at the Lynda Jackson Macmillan Centre.

Contacts

If at any time during your course of chemotherapy you become unwell you must contact one of the numbers below:

Chemotherapy Suite 020 3826 2236
[Mon - Fri, 8am - 8pm]

Ward 10 (mainly for men) 020 3826 2022
[24 hours]

Ward 11 (mainly for women) 020 3826 2040
[24 hours]

**24 hour Acute Oncology Service
Mount Vernon Cancer Centre: 07825 028855**

The name of your consultant is:

Your clinical nurse specialist is:

Your chemo clinical nurse specialist:020 3826 2233
or 07825 025294

Pharmacy (Chemotherapy Suite):020 3826 2238
[Mon - Fri, 10am - 4pm]

If you have any questions or would like further information about your chemotherapy:

Lynda Jackson Macmillan Centre:020 3826 2555
[Mon - Fri, 9.30am - 1pm & 2pm - 4.30pm]

Contents

Introduction 4
 Who will be looking after me? 4
 What is chemotherapy? 5
 How do the drugs work? 5
 How is chemotherapy given? 6
 Your chemotherapy ALERT CARD 6
 Will chemotherapy hurt? 7
 Must I always be admitted to a ward? 8
 One visit treatment 8
 Two visit outpatient treatment 10
 How often must I have chemotherapy? 12
 How long will my treatment last? 12
 How often must I have blood tests? 12
 What are the possible side-effects? 12
 What about my work and leisure activities? 19
 What about my holidays? 19
 What about my nutrition and diet? 20
 Will the chemotherapy affect my sex life? 20
 What about my fertility? 21
 What about my other medicines? 22
 Should I have a flu vaccination? 22
 Am I allowed alcohol during treatment? 23
 What about smoking? 23
 What if I feel unwell? 24
 What can I do to help myself while receiving chemotherapy? 24
 Car parking at the hospital 25
 Getting help with paying for transport 26
 Can I record my discussion in clinic? 26
 What if I have more questions? 26
 Contacts 27

Getting help with paying for transport

If you are on a low income, you may be eligible for help with paying for the cost of transport to and from the hospital. This includes bus and train fares and car mileage but not taxi costs.

For further information about eligibility, please speak to Patient Affairs (020 3826 2343) or visit www.direct.gov.uk and search for 'Travel costs'.

Can I record my discussion in clinic?

Yes. You may want to record your discussion with the doctor or nurse on a small device (eg smartphone). This may be helpful to you when remembering information later and discussing it with your family or friends. If you would like to do this, please say at the start of the appointment that you will be recording so the staff are aware. We will make a note that the consultation was recorded and who was present, to make it easier if you need to refer to it later. Please be aware that we do not allow video recording.

What if I have more questions?

Write them down in the space below and ask a member of your treatment team or staff in the LPMC to help you find answers.

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Car parking at the hospital

A Pay & Display parking scheme operates 24 hours a day. Cancer patients have a £1 concessionary parking rate but must register for this. Registration forms are available at the Cancer Centre Reception desks or on the back of appointment letters. Take your registration form to the Facilities Office or Car Parking Office on your first visit and you will be given a yellow Concessionary Parking Pass. Facilities Office or Car Parking Office: Monday - Friday, 8am - 12 and 1pm - 4pm.

- For car parks accessed via Gate 1 or Gate 3: get a Concession/Blue Badge ticket for £1 at the Pay and Display machine and display this and your yellow pass on the car dashboard. Your yellow pass can be used in any car.
- The car park accessed via Gate 2 is Pay on Exit: type your car registration number into the machine when you are ready to leave. You will be charged £1 and the barrier will rise automatically. You do not need to display your yellow pass in this car park, but only the car registered can be used there.

Blue badge holders do not need to register. Pay £1 at the Pay & Display machine. Please display your ticket and blue badge on your dashboard.

Introduction

Your cancer specialist¹ has recommended that your cancer is treated with a course of chemotherapy.

This leaflet is a simple guide to chemotherapy, we hope it will answer some of your questions.

If you have any further questions before, during or after your treatment, please speak to one of the team treating you - there are also some useful contact telephone numbers at the end of this booklet.

Who will be looking after me?

A specialist cancer doctor is called an oncologist.

He works with a multidisciplinary team (MDT) to plan and oversee your treatments.

You will be seen each time you come for your treatment by either the doctor or a nurse before you have your chemotherapy. Your chemotherapy will be given by a specially qualified chemotherapy nurse.

The MDT looking after you can include:

- specialist nurses
- dieticians
- pharmacist
- surgeons (if needed)
- histologists
- Allied health professionals

¹ During this leaflet we will refer to your cancer specialist/oncologist and any doctors working within his/her team as your doctor or hospital doctor

What if I feel unwell?

Please call the 24 hour Acute Oncology Service at Mount Vernon Cancer Centre **straightaway** if you experience signs of infection, including:

- a serious cough
- feel breathless
- a raised temperature of 38°C or higher, or 37.5°C for more than one hour
- shaking chills

If you have concerns about any of the following symptoms, please ring one of the telephone numbers at the end of this leaflet for advice:

- nosebleeds that are difficult to stop
- red purple spots under the skin or easy bruising
- soreness of the mouth or throat
- diarrhoea or constipation

What can I do to help myself while receiving chemotherapy?

- drink plenty of fluids
- maintain a balanced diet (little and often)
- continue to maintain as normal a lifestyle as possible including light exercise
- maintain good mouth care
- avoid exposure to the sun
- keep a thermometer in your home and check your temperature if you feel unwell
- call if you feel unwell or have questions and concerns

What is chemotherapy?

Chemotherapy is drug treatment, which is normally given to treat or control cancer.

Chemotherapy is often given with surgery or radiotherapy. If it is recommended for you the doctor will explain the details.

You will be asked to attend a pre-chemotherapy consultation on a separate day before starting your treatment. At this visit you will be given information about the process involved in giving your chemotherapy and how to manage possible side-effects. You may ask questions and talk to the chemotherapy nurses about anything that is worrying you.

How do the drugs work?

There are many drugs which kill cancer cells and control the disease. Individual drugs attack the cells in different ways; some break down parts of the cell and some disrupt the cell's growth cycle at different stages.

Chemotherapy is most effective against rapidly dividing cells, such as in cancer, but the drugs may affect some normal cells as well. The effect on the normal cells is usually temporary, as they have the ability to repair at a faster rate than cancer cells.

How is chemotherapy given?

Your chemotherapy will be given by a specially qualified chemotherapy nurse.

Chemotherapy is given in many ways, including:

- by mouth - as tablets or capsules
- by injection directly into a vein - this can be given by using a syringe or by an infusion (drip)
- by continuous infusion using a special infuser

Injected treatment may be given through a small catheter (cannula) inserted into the hand or arm, via a Hickman line, PICC or a Port. These will be explained (if relevant to you) by the nurse.

Chemotherapy can be given in conjunction with other drug therapies and/or supportive medication.

You may have one drug, several drugs together or different drugs at specific times. The doctor, nurse or ward staff will explain your drug treatment to you.

Your chemotherapy ALERT CARD

You will be given a chemotherapy ALERT CARD to carry with you at the start of your treatment. If you have an appointment with any health care professional including your GP or dentist or to attend hospital for any reason, please take the card with you and show it to whoever is treating you.

Am I allowed alcohol during treatment?

Usually it is quite safe for you to have a small glass of alcohol, such as wine or beer while you are having chemotherapy if you feel like it. However, there are some chemotherapy drugs which do not go well with alcohol. Please ask your oncologist or pharmacist about this subject.

What about smoking?

Your oncologist will discuss this with you and will recommend that you give up smoking both during treatment and afterwards.

Giving up smoking will ensure you give yourself the best chance to recover from cancer. This is because nicotine in cigarettes causes the blood vessels to shrink (vasoconstriction) and this may make your treatment less effective.

You may want to consider not re-starting to smoke after your treatment has finished. If you do smoke there may be an increased risk of some long term side effects. If you want more information, please ask your oncologist or nurse.

Leaflets to help you give up smoking are available from the LJMC.

You can also contact the
NHS smoking helpline: 0800 808 0000 (7am – 11pm)
www.smokefree.nhs.uk

If you normally pay for NHS prescriptions

People undergoing treatment for cancer do not have to pay NHS prescription charges if they have a valid medical exemption certificate.

To get an exemption certificate, ask your GP for an application form.

What about my other medicines?

It is important that you tell your doctor or pharmacist about any other tablets, injections or medicines you are taking. This includes any vitamins, herbal medicines and 'over the counter' preparations as they may interact with your treatment.

If you have any questions about your medication, please ask. If you have to come into hospital, please bring all your medicines with you.

Should I have a flu vaccination?

It is important that all patients having chemotherapy have their seasonal flu vaccination if possible, before they start their chemotherapy. Any family members living in the same house should also have the flu vaccination. For full details about this read our leaflet HHC257 - 'Seasonal Flu Vaccination'.

It is important to remember that anybody having chemotherapy must not have any live vaccinations.

Will chemotherapy hurt?

Chemotherapy should not hurt. If you have any pain, stinging, burning or any unusual sensation as you are having treatment it is very important to tell the nurse giving you the drugs, when it happens. The nurse will check that the cannula is working well. She will also check the area for any redness or swelling.

Sometimes the drugs can leak into the tissue around your vein. This is called an 'extravasation'.

An extravasation can often be resolved very easily with little or no damage to the skin, but some drugs called 'vesicants' can cause painful skin ulcers if they leak into the tissues. It is very important that you tell the staff treating you straightaway if you have any discomfort at all whilst having your chemotherapy. This is because treatment can be given to help stop or limit any damage if there is an extravasation.

Sometimes damage to the tissues does not appear straightaway. It can develop over the days after the chemotherapy. When you go home, if you have increased pain, swelling or redness around the area where the chemotherapy was given you must contact the hospital at once.

Must I always be admitted to a ward?

If you are having chemotherapy overnight or longer, you will be admitted to one of the inpatient wards.

The length of stay depends on the kind of treatment your oncologist has prescribed.

Some patients will attend the Chemotherapy Suite or the Marie Curie Day Unit for their treatment. These are day units and are open Monday to Friday. You will need either one or two visits for your treatment. Your team will discuss this with you. The length of time it takes to give your treatment will depend on the type of chemotherapy you are receiving.

One visit treatment

When you arrive

After your blood sample has been taken you may see your consultant or one of the doctors on the team in clinic. If you do not need to see a doctor, you will be assessed by a chemotherapy nurse.

If your blood count (test result) is not high enough for you to have your chemotherapy, you will be asked to come back another day. This will probably be the next week. This is to give the blood cells time to recover. In this case, please make sure you see the receptionist to book another appointment before you go home.

If your blood results show that you are able to have your chemotherapy, your chemotherapy will be prepared by the specialist unit. This process can take up to 3 hours as it is made specially for each patient. You will then have to wait for your chemotherapy drugs to be checked by the pharmacist and delivered, which may take up to another hour.

This is only a general leaflet. We strongly advise you to discuss these important issues with your oncologist or chemotherapy nurse to understand what you should do with regards to contraception in your case.

What about my fertility?

Chemotherapy may make you sterile, either temporarily or in some cases permanently.

Men

It is possible for men to arrange to store their sperm before the chemotherapy begins. Please discuss this with your oncologist before your treatment begins.

Women

It may be possible for women who were hoping to have a child in the future to be referred to a fertility clinic. Please discuss this with your oncologist before your treatment begins.

Women whose menstrual periods are regular before chemotherapy begins, may find that they are not so regular, or may even stop during treatment. Your periods may or may not restart after chemotherapy has finished.

Even if your periods stop it is still possible to become pregnant, so you must continue using barrier contraception.

Everyone's situation is different so, if you have any concerns relating to fertility issues, please discuss them with your oncology team. The LJMC has information available from Macmillan Cancer Support: Cancer treatment and fertility for men and women.

What about my nutrition and diet?

It is important for your body to receive the right kind of food so you should try to eat well while you are having your treatment. If you have problems when eating, or you have any difficulties with your digestion, there is a dietician at the centre who can help you work out an eating plan to try to prevent weight loss. Some chemotherapies can result in weight gain, please ask your treatment team if you are worried.

Will the chemotherapy affect my sex life?

You should be able to continue your normal sex life while you are having treatment unless you have been told you should not - for example, if your platelet count is low. You may find your interest in sex (libido) is less during your treatment. This may be because you feel tired. Your interest in sex should return to normal when your treatment is finished.

It is important for women **not** to become pregnant and for men not to father a child, while they are having chemotherapy. The length of time to avoid being pregnant can be different for each patient. Please discuss this subject with your oncologist.

If you think there is a chance, however small, of you or your partner becoming pregnant during chemotherapy, it is important to inform the medical team as soon as possible. If you are taking the contraceptive pill or using another hormonal method of contraception, please check with your hospital doctor that it is safe for you to do so.

Whilst waiting

You are welcome to bring a book, Kindle, iPod or laptop. During this time you can get some food and drinks, visit the Lynda Jackson Macmillan Centre or visit the Comfort Fund's shop, book shop or charity shop on the Mount Vernon Hospital site.

Please check with your nurse first but you may be able to leave the hospital to have a break if you wish. There are local pubs which serve lunch and shops you could visit in Northwood.

If you have a mobile phone, please leave your number with your nurse or the receptionist. If you live nearby you can go home, but please make sure we have your phone number. We will ring you when your drugs are ready.

Having your treatment

A cannula (a fine flexible tube) will be placed in one of the veins in your arm unless you have a port, PICC or Hickman line. Whilst you are receiving your chemotherapy, a member of the pharmacy team or your nurse will give you any more drugs you need to take home. They will explain what they are and when to take them.

When your treatment is finished the cannula will be removed.

Remember to get a form for your next blood test and make your next appointment with the nurse/receptionist before you leave. If you need medication to take home, check that you have it with you.

Two visit outpatient treatment

If you are a two visit patient you will receive two appointments. The first is your medical review (clinic appointment) when you will see your doctor to prepare for your treatment and the second is to receive your chemotherapy in a day unit.

First appointment (clinic appointment)

Check in with the Cancer Centre Reception. You will be sent to the pathology department for a blood test if you have not already had one. After your blood sample has been taken you may see your consultant or one of the doctors on the team.

If you need extra medication as well as the drugs that have already been prescribed, please make sure that you get a prescription at this stage from your hospital team.

If your blood count (test result) is not high enough for you to have your chemotherapy, you will be asked to come back another day. This will probably be the next week. This is to give the blood cells time to recover. In this case, please make sure you see the receptionist to book another appointment before you go home.

You may not need to see your doctor before each chemotherapy treatment. If this is the case, you may still need to have your blood sample taken and a nurse will contact you a day before your chemotherapy for a telephone assessment.

What about my work and leisure activities?

Some patients find that they can manage to carry on working between treatments. It is important that you try to pace yourself and plan your work and other activities according to how you feel.

It is important to try and avoid contact with people with coughs, colds or obvious infections.

What about my holidays?

You should discuss your holiday plans well before the date you wish to go. This is so that, if at all possible, your treatments can be arranged for before or afterwards.

Be careful not to spend long periods in the sun or sunbathing while you are having chemotherapy drugs. This is because your skin can be more sensitive to the sun. Please ask your oncologist if you are not sure about what to do.

Use a high factor sun cream (factor 20 or above). Don't stay in the sun during the hottest part of the day between 11am - 3pm. Wear a hat if you go in the sun for any length of time. If you are planning an overseas holiday, you must first speak to your oncologist to make sure it is safe for you to go abroad.

You must also speak to your oncologist before having any special vaccinations which are recommended for the place you hope to visit. (You may find Macmillan's information on travel helpful).

□ Constipation

Some of the anti-sickness medication given with your chemotherapy can slow your bowels (constipation). If you are having difficulty opening your bowels, please ask your treatment team which laxatives to use in the first few days following treatment.

Constipation can make you feel unwell if you don't treat it so please contact your treatment team if you need advice.

Tiredness (fatigue)

You may feel tired and lethargic during your treatment, especially towards the end of the course and after it has finished.

Tiredness is very common. It can last for different lengths of time. Try to stay as active as possible, but it is important to take breaks and not do too much at one time. You should plan rest breaks. Try to take short naps, as long as they do not stop you sleeping at night.

Tiredness usually follows a pattern. A leaflet called 'How did you feel during Your Chemotherapy? Your Personal record (PI 52)' can help you identify a pattern and aid management. Please ask for a copy of the leaflet.

Please note that the LJM produces a leaflet, PI76 - 'Now that you have started your chemotherapy' and other helpful hints to help you deal with different side-effects and with other issues associated with cancer.

Second appointment (chemotherapy)

This appointment will be for your chemotherapy in the Chemotherapy Suite/Marie Curie Day Unit. When you arrive you will need to check in with the day unit receptionist.

Your chemotherapy drugs will have been prepared ready for your appointment, so you should not usually have to wait more than an hour for your chemotherapy. A cannula (a fine, flexible tube) will be placed in one of the veins in your arm unless you have a port, PICC or Hickman Line.

If needed, you will be given some anti-sickness medication, either to take by mouth or as an injection through the cannula.

The length of time it takes to give your chemotherapy can vary. This depends on the type of treatment you are having. Your nurses will explain how long your treatment will take.

While you are having your chemotherapy, a member of the pharmacy team or your nurse will give you any drugs **that have been prescribed** which you need to take home. They will explain what they are and when to take them. There is more information about the drugs you may be given to take home later in this booklet.

When your chemotherapy is finished

When you have finished your chemotherapy, your nurse will take the cannula out of your arm and you can go home.

Before you leave, check that you have a form for your next blood test and make your next chemotherapy appointment with the day unit receptionist or nurse. If you need medication to take home, check that you have it with you.

How often must I have chemotherapy?

This will depend on the drug treatment selected for you.

Each course of treatment is usually followed by a 'rest' period. This is so that normal cells have a chance to repair themselves but not long enough for the cancer cells to recover.

Treatment schedules vary and may be given:

- once a week
- once every 2, 3 or 4 weeks
- daily for up to 10 days
- continuously with a drip over a period of 1 - 5 days
- continuously through an infuser system

How long will my treatment last?

A course of treatment including the rest period is called a cycle of treatment. Your type of cancer and the drugs you receive will determine how many cycles of chemotherapy you have.

How often must I have blood tests?

You will usually require a blood test before each cycle of chemotherapy.

What are the possible side-effects?

Please remember that everyone reacts differently to chemotherapy. Some people have no side-effects at all.

After your first cycle of chemotherapy, you will have an idea of which side effects (if any) may affect you.

- try to drink plenty of fluids
- it may be better to eat small meals
- you may find it easier to eat low-fat foods
- if you feel sick, avoid spicy and strong-smelling food
- if you have nausea, you may find it helps to eat dry crackers or toast
- fizzy drinks help to settle the stomach
- foods containing ginger may also help

Some people find that keeping busy, reading or watching television can take their mind off the feeling of sickness.

Relaxation techniques, reflexology or aromatherapy may also help in managing nausea or any other symptoms from having your chemotherapy. Contact the LJM for further information about these therapies.

- Diarrhoea (passing loose stool 4 times or more than your normal routine)

This can occur with a few of the drugs but can usually be controlled with medicines. It is important that you drink plenty of fluids during this time, to stop you becoming dehydrated.

If the diarrhoea continues for more than two days or is not controlled by your medication, please contact your treatment team.

If you need dental treatment during chemotherapy, please ensure your dentist sees your ALERT CARD and is aware you are receiving chemotherapy.

If you develop mouth ulcers or white patches on the tongue or inside of your mouth, call your oncology team for advice (see Contacts numbers at the end of this booklet).

- Taste and smell changes
You may notice changes to your taste and smell with some chemotherapy drugs. This may continue during the treatment.

Sucking a strongly flavoured sweet at the time of injection may help. Your taste may change during your treatment, but this should not be permanent.

- Nausea and sickness
Some chemotherapy drugs can cause you to feel sick or be sick. Not all chemotherapy causes this side-effect. If nausea is a side effect of your treatment, your doctor will prescribe anti-sickness medicine.

The anti-sickness medicine will be given before the start of chemotherapy. You will be given some to take regularly at home for 3 days as needed.

You must tell your nurse or doctor if the nausea goes on for more than a few days, or you are being sick even though you are taking your medication. There are many different anti-sickness medicines that can be used to try to prevent this from becoming a problem.

Nausea may last for a few days and listed below are some simple ways to help yourself.

Bone marrow suppression

Chemotherapy can affect the blood cells which are made in your bone marrow causing your blood cell count to drop during your treatment. This is called bone marrow suppression.

Blood cell counts may drop too low if they do not have enough time to multiply properly and for this reason the treatment has rest periods. Chemotherapy may have to be delayed if your blood cell counts are too low to give your body extra time to recover.

The kinds of blood cells which may be affected by the chemotherapy are:

- White blood cells

These cells help you to fight infection. If your white blood cell count drops after chemotherapy, you are more likely to get an infection and your body may not be able to deal with it normally.

Signs of infection may be a raised temperature (of 38°C or higher), shaking chills, feeling hot and sweaty or a general feeling of being unwell.

If you have any of these signs, **contact the hospital immediately** as a blood test and/or antibiotic treatment may be needed (see the contact details on your Alert card or use the 24 Hour Emergency advice line number on page 23). **Do not** be tempted to leave this until the next day.

If possible during your course of chemotherapy, try to avoid people with coughs, colds or obvious infections.

Platelets

Platelets help your blood to clot. If your platelet count falls, you may notice that you bruise more easily than usual. Small red-purple spots may appear under the skin, or your nose or gums may bleed. Please let your team know if you experience these symptoms (see Contacts at end of this booklet).

Red blood cells

These cells carry oxygen to all parts of your body. If they are affected by the drugs, you may feel tired and look pale or you may be short of breath. Please let your team know using the contact numbers at end of booklet. Sometimes this may mean you will need to have a blood transfusion.

Skin

Sometimes some drugs can cause slight discolouration along the veins or dryness of the skin. If this happens you can use any moisturising cream. If you develop a rash, please call your healthcare team (see Contacts at the end of this booklet).

Hair

Not all chemotherapy drugs cause loss of hair, but some do. Any loss is usually gradual. Sometimes there is no loss of hair, sometimes only thinning and sometimes complete loss of scalp hair and maybe even all body hair. The scalp may also be a little tender or sore.

If you experience any hair loss, remember that for **most** patients this is only temporary and your hair should grow again when the drugs are stopped. During this time some patients like to wear a wig, hat or headscarf.

The Lynda Jackson Macmillan Centre has information on hair loss, headscarves and wigs.

Recent research is showing that some chemotherapy drugs **may** cause permanent hair loss. Please speak with your team to see if this is a risk and if you have any concerns. They can also discuss if scalp cooling is an option.

Urine

Some chemotherapy drugs are coloured red or blue and cause your urine to change colour temporarily (normally for 24 - 48 hours) to red, green or blue; this is harmless and should not worry you. If you notice any blood or blood clots in your urine you should tell your nurse or doctor.

As chemotherapy can be present in your urine for a few days following your treatment, if there is any spillage outside the toilet, it is important to clean the area and wash your hands.

Digestive tract

You may experience:

- Soreness of the mouth and gums (stomatitis)

Keeping your mouth clean is very important.

If possible, brush your teeth twice daily and rinse after each meal to remove debris and to reduce the risk of infection. You may use mouthwash, but avoid those which contain alcohol. Your local pharmacist will be able to advise you.

If you experience a sore mouth, try to avoid eating spicy, very hot or cold food or acidic food such as citrus fruits. Smoking and alcohol can also increase the soreness.