

Now that you have started your Systemic Anti-Cancer Therapy (SACT)

Please bring this with you every time you attend for treatment

Patient Information Series Pl 76

Patient label

SACT regimen:

Scheduling:

Consultant:



Contacts

If at any time during your course of chemotherapy you become unwell you must contact:

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

Questions about your medication:

Pharmacy (Chemotherapy Suite): 020 3826 2238

[Mon-Fri, 10am-4pm]

or for non-urgent queries:

ENHT Pharmacy Helpline email: medinfo.enh-tr@nhs.net

Now that you have started your Systemic Anti-Cancer Therapy (SACT)

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If at any time during your course of chemotherapy you become unwell you must contact:

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

See the list of side effects to watch out for on page 5

Introduction

Welcome to Mount Vernon Cancer Centre (MVCC).

This leaflet is written for patients and provides a step-by-step guide to your treatment day/days and tips on managing some of the side effects you may experience.

Side effects vary from person to person and depend on the treatment regimen. You might get only a few or mild side effects. It is not possible to say definitely how you will be affected. Please speak with a member of your treatment team if you have any concerns. There are many things that they can do to help you cope.

Most side effects will gradually go away after your treatment finishes

What should I do if I experience side effects?

You should have received information about your treatment and its possible side effects. You may also have been prescribed medication to help with side effects.

If you have any concerns about side effects, call the **24-hour Acute Oncology Service (AOS)** on:

07825 028855

Use the table on the next page to help you decide if you should call.

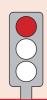
- O Don't delay in calling if your problem is listed in the **RED** box call immediately
- For **some** red problems, you may be told to call 999
- If you experience two problems in the **AMBER** box, call the AOS number

AMBER + AMBER = RED

• If you have symptoms or problems that are not listed here, call the AOS number

Call the AOS number **immediately** if you have any problems that are listed in this box:

- O Chest pain call 999
- Difficulty breathing call 999
- Generally unwell
- Shivery episodes or flu-like symptoms
- O Temperature above 37.5°C
- Temperature below 36°C
- O Diarrhoea (4 or more loose bowel movements in 24 hours)
- Being sick (vomiting)
- Bleeding or unusual bruising
- Swollen or painful legs
- Sore mouth that stops you eating or drinking



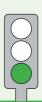
Call the AOS number within **24 hours** if you have any problems listed in this box. Call **immediately** if your symptoms get worse:

- Sore mouth but can still eat and drink
- Itchy or painful skin changes
- Sore, watery eyes
- Increase in pain
- Constipation
- Feeling sick (nausea)
- O Diarrhoea (2-4 loose bowel movements in 24 hours)



Be vigilant and call the AOS number if they get worse or continue:

- Tiredness
- Skin changes that are not itchy or painful
- Mood changes
- Difficulty in coping with the treatment
- Loss of appetite



What can I do to help myself while having Systemic Anti-Cancer Therapy (SACT)?

We recommend you:

- drink plenty of fluids
- usually it is quite safe for you to have a small glass of alcohol, such as wine or beer while you are having treatment 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
- maintain a balanced diet (little and often)
- carry on having as normal a lifestyle as possible, including light exercise
- maintain good mouth care
- avoid prolonged exposure to the sun
- keep a medical thermometer in your home. If you have a temperature of 38°C or above (or 37.5°C for more than 1 hour), call the Acute Oncology Service on 07825 028855
- call the Acute Oncology Service on 07825 028855 if you feel unwell (even if you have no increase in temperature) or have questions and concerns
- keep your ALERT card in your wallet and show it to any health care professional that you may need to see, including your GP and dentist
- remember to 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
- keep a record of any side-effects in the personal record - see page 21 of this booklet

What can I do if I feel sick (nausea) or vomit?

You may have been sent home with anti-sickness medicine.

If these are not helping, please contact the 24 hour Acute Oncology Service for advice on other medications listed in the tables below.

Common anti-sickness drugs

| Drug | How to take | General advice and common side-effects |
|--|--|---|
| Dexamethasone* (steroid) Available as soluble tablets, liquid or injection *Haematology patients may not receive steroids. | Take your tablets with breakfast and lunch to help prevent them affecting your sleep and upsetting your stomach. | Steroids can disturb your sleep and cause indigestion. If you feel a burning sensation or pain in your stomach please tell your doctor or nurse at your next clinic appointment. Feeling 'flushed' or 'red faced' can be a normal reaction while you are taking steroid tablets. |
| | | Diabetic patients: Dexamethasone may increase blood sugar levels. If you have diabetes, you should monitor your blood sugar level closely. Tell your doctor or nurse if these levels become uncontrollable or do not return to what is normal for you once the steroids have stopped. |
| Ondansetron Available as tablets, liquid, suppository or injection | Take twice each day to prevent the feeling of sickness. | Can cause constipation. If you have not had a bowel movement for 1- 2 days, start Senna (see page 11-12). If this does not work contact your doctor/nurse. |

| Aprepitant Available as capsules | One 125mg capsule is taken at least one hour before treatment and then one 80mg capsule each day for two days after treatment. | If you have not taken this capsule before arriving, alert the staff as you will need your capsule at least 1 hour before your treatment starts. Aprepitant is only used for patients whose treatment causes severe nausea. |
|---|--|--|
| Domperidone Available as tablets, liquid, suppository or injection | Take 30 minutes before meals as directed. Not normally taken for more than one week. | This drug works by helping food move faster through your stomach. This helps to prevent feeling and being sick. Domperidone also comes in a suppository. This is useful if you feel too sick to swallow tablets. |
| Cyclizine Available as tablets or injection | Tablets are usually taken three times a day only when needed. | This may make you drowsy. You should not drive a car or operate machinery when you are drowsy. |
| Lorazepam Available as tablets. | Your doctor will ask you to put half a tablet under the tongue the night before and/or on the morning of treatment. | This is usually taken with other types of medicines to minimise feeling and being sick. They may make you drowsy. You should not drive a car or operate machinery when you feel drowsy. |

If you have any queries about using any of these drugs please contact the Mount Vernon Hospital pharmacist (see page 2).

If you are taking **Capecitabine** tablets and vomit more than once in 24 hours or find it hard to eat or drink, stop taking Capecitabine and contact the Cancer Centre (see page 2).

Helpful tips for managing nausea

This information is a guide to help you deal with feeling sick (nausea) or being sick, until you can talk to your doctor. It does not replace medical advice. If you are currently taking anti-sickness medicines and you are still feeling sick, you should tell your doctor. There are other options available.

The feeling of nausea is usually temporary. It is important to try to take some food during this time, as being hungry can sometimes make it worse.

The following tips may help to overcome this and help you to eat:

- try to avoid preparing food when you feel sick. Use ready meals/tinned foods
- O accept an offer to have food made for you
- try to keep away from cooking smells. Microwave cooking produces less smell. You may want to try eating ready prepared meals. Some patients find that eating cold food and having cold drinks is easier as they have less smell
- O avoid eating greasy/fried food and hot/spicy foods
- try to have food which you fancy and eat smaller meals more often e.g. six small snacks per day
- keep meals fairly dry
- good mouth care is important so gently clean your mouth and teeth after every meal
- if you feel sick in the morning, try eating a cracker or a dry biscuit before getting out of bed
- O don't drink a lot of fluids before meals, or with meals. Wait for half an hour after food before having a drink
- when drinking, try taking sips slowly. Some patients find sipping a fizzy drink such as soda or dry ginger ale or having ginger tea can help

- try getting some fresh air before meals to distract you from the thought of food
- avoid tight or restrictive clothing
- try rinsing your mouth with fizzy water between meals
- suck ice cubes
- try to sit down and relax, but avoid lying down straight after eating

Can complementary therapies help?

Acupressure bands (available from chemists) can help to control feelings of sickness. These apply pressure to specific parts of the body, usually the wrist.

Complementary therapy and relaxation sessions may also help. Please ask in the Lynda Jackson Macmillan Centre (LJMC) for more details or see leaflet PI16 A Patient's Guide to Complementary Therapies at Mount Vernon Cancer Centre.

Further information about feeling and being sick

- Controlling nausea and vomiting (anti-emetic therapy) Macmillan Factsheet www.macmillan.org.uk
- Types of anti-sickness drugs; How you take antisickness drugs; Side effects of anti-sickness drugs – Cancer Research UK leaflets www.cancerresearchuk.org

These leaflets are also available from the LJMC.

If you would like further advice, please contact the Mount Vernon Cancer Centre Dietitian, tel: 020 3826 2125.

What can I do if I am constipated?

You may have been sent home with medicine to take if you become constipated.

If these are not helping, please contact the 24 hour Acute Oncology Service for advice on other medications listed in the tables below.

Drink plenty each day and try to get some light exercise when you are able. Even a 10 minute walk can help your bowels to function.

Common medications for constipation

| Drug | How they work | General advice and common side-effects |
|--|---|--|
| Stimulant Laxatives such as Senna tablets and liquid, Glycerin suppositories, Docusate capsules, | Increase the activity of the bowel. | For both stimulant laxatives and stool softeners: tablets and liquids are usually taken at night with a glass of water. Suppositories are inserted |
| Bisacodyl tablets | Docusate is a stimulant and stool softener. | deep into the rectum. Wash hands well before and after inserting the suppository. Remove |
| Stool Softeners such as Liquid Paraffin | Provide moisture to the stool. | the suppository from the protective film and moisten with water before inserting it into the rectum. Do not swallow the suppository. Senna usually acts in 8 – 12 hours. Docusate usually acts within 1 – 2 days. |

| Osmotic laxatives such as Lactulose syrup, Macrogols | These draw water into the bowel to soften the stool. These may take 48 hours or more to act. | Where necessary, the required amount of granules should be mixed with about half a glass of water or follow the instructions given to you. Stir well and drink it straight away. |
|---|--|---|
| Bulk forming laxatives such as Ispaghula, Sterculia | These are fibre supplements that increase the fibre in your diet helping your bowels work more efficiently. Full effect may take some days to develop. | The amount of granules or powder needed should be mixed with about half a glass of water or follow the instructions given to you. Stir well and drink it straight away, preferably after meals. These products should not be taken just before going to bed. You must remember to drink plenty of fluid while taking fibre supplements to avoid obstruction (blockage). |
| Codanthramer capsules/syrup | A combined stimulant laxative and stool softener. This medication takes 6 - 12 hours to work, so works well when taken at bedtime. | Urine may appear red or pink after taking this medication. After opening your bowels, clean the area well as irritation, redness or discolouring of the skin around the back passage may occur since the medicine is present in the urine and stools. |

If you have any queries about using any of these drugs please contact the Mount Vernon Hospital pharmacist (see page 2).

Helpful tips for managing constipation

This information is a guide to help you deal with your constipation until you can talk to your doctor. It does not replace medical advice.

Managing your diet

It is important for everybody to eat fibre in their diet. If you have constipation you may benefit from eating more fibre. The following tips may also help:

1. Eat a balanced diet

Make sure that you eat more fibre each day than usual. Fibre is the name given to parts of plant foods that we cannot completely digest. Eating fibre relieves and prevents constipation. If you are not used to eating fibre, then introduce it gradually.

Foods which are high in fibre include the following:

- wholegrain breakfast cereals
- O wholemeal bread and flour
- O brown rice
- O wholemeal pasta
- fresh fruit and vegetables with their skins
- O beans and nuts
- O dried fruit such as figs, prunes, apricots or dates

If you have a very poor appetite, have difficulty chewing or swallowing or have been asked to follow a low residue diet, increasing the fibre in your diet may not be correct for you. Please ask your medical team or ask for a referral to the dietitian

If this does not help, or the constipation lasts more than three or four days and you are having abdominal pain, please tell your doctor.

2. Drink plenty of fluids

Make sure you drink plenty of fluids. You should aim to drink at least 8–10 glasses each day. Avoid alcohol.

3. Try some natural remedies

You may want to try taking natural remedies such as syrup of figs and prune juice which may help.

4. Try some exercise

It is important to do some gentle exercise such as walking each day.

If you cannot walk by yourself then ask a friend, carer or relative to go with you.

5. Further information if you have constipation

- Managing the symptoms of cancer (Macmillan Cancer Support (MCS) booklet)
- Healthy eating and cancer (MCS booklet)

These are available from the Lynda Jackson Macmillan Centre or from Macmillan Cancer Support at www.macmillan.org.uk

What can I do if I am having diarrhoea?

You may have been sent home with medicine in case you get diarrhoea.

If you have **not** been sent home with medication for managing diarrhoea, please contact the 24 hour Acute Oncology Service for advice. They will decide if the diarrhoea is a side effect of your treatment and advise you how to manage it. Do not take any over-the-counter medication for diarrhoea until you have spoken with your health care team.

You should aim to drink 8–10 glasses of water each day

If you have diarrhoea that is not helped by your medication please contact the Acute Oncology Service (see page 2).

Common anti-diarrhoeal drugs

| Drug | General advice | How the drug is given |
|----------------------|--|--|
| Loperamide | This is used to treat sudden, short-lived attacks and long-lasting diarrhoea in adults. It works by slowing down gut movement and making the stools more solid and less frequent. If you already use Loperamide for a chronic condition, please discuss your dose with your doctor or nurse. | When diarrhoea starts, you will usually take two capsules to begin with and then one after each episode of diarrhoea. Never take more than eight capsules in any 24 hour period, unless your doctor or nurse has said that this is safe for you. |
| Codeine phosphate | This belongs to a group of medicines known as opioid pain killers. These are used to relieve pain, suppress cough and treat diarrhoea. Do not take the tablets for longer than is needed. | The usual dose for adults is one or two 30mg tablets, three to four times a day. No more than eight tablets must be taken in 24 hours. These may make you feel drowsy and light headed. If they do, you should not drive or operate machinery. |

If you have any queries about using any of these drugs please contact the Mount Vernon Hospital pharmacist (see page 2).

If you are taking **Capecitabine** tablets and have 4 loose bowel movements per day more than usual or diarrhoea at night, **stop** taking Capecitabine straight away and contact the **Acute Oncology Service** (see page 2).

If you are taking **Irinotecan** and experience any diarrhoea, please contact the **Acute Oncology Service** (see page 2).

Helpful tips for managing diarrhoea

This information is a guide to help you deal with the symptoms of diarrhoea until you can talk to your doctor. It does not replace medical advice. If your symptoms persist you must inform your doctor.

Managing your diet

It is important for everybody to eat fibre in their diet but if you have any symptoms of diarrhoea, eating fibre will make them worse.

1. Reduce the amount of fibre you eat each day

High fibre foods may make your symptoms worse and you should eat less of it than usual. You will need to check with your doctor or dietitian how long you should do this for.

High fibre foods to avoid include:

- wholegrain breakfast cereals
- O wholemeal bread and flour.
- O brown rice
- O wholemeal pasta
- fresh fruit and vegetables with their skins
- O beans and nuts
- O dried fruit such as figs, prunes, apricots or dates

2. Be careful about eating other foods which may make your symptoms worse, so eat less of them.

These include:

- Spicy foods
- O rich, greasy, fried foods
- foods containing caffeine (coffee and chocolate)
- dairy products (milk, butter, yogurt, cheese, cream)
- very cold or very hot drinks
- products containing sorbitol (sugar-free mints or gum)

3. Eat foods which may help your symptoms by making your stools firmer

| These inc | lude: | |
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| | | |

- chicken (without the skin on)
- chicken soup
- O fish
- O eggs
- O rice and pasta
- potatoes (but without skins)
- O bananas
- O white bread
- cooked fruit (particularly stewed apple)
- O low-fibre breakfast cereals such as cornflakes
- O dry crackers

Try having drinks at 'room' temperature.

If you have diarrhoea, this may put you off eating. It may help if you eat smaller amounts of food more often, rather than trying to eat large meals.

4. Drink plenty of fluids

When you have the symptoms of diarrhoea, you lose fluids. It is important that these are replaced so you don't get dehydrated. Drink as often as you can, even if it is only small amounts. Avoid alcoholic drinks. The best types of fluids to have include:

- O water
- O clear soups
- any soft drinks (except 'diet' products). If fizzy, let them go flat

Electrolyte sachets can also be bought from a pharmacy. These help to replace minerals lost through diarrhoea. Please ask your pharmacist for information about when to take these.

What can I do if my mouth is sore?

You may have been sent home with pain relief medicine and mouth washes.

If these are not helping, please contact the 24 hour Acute Oncology Service for advice on other medications listed in the table on the next page.

Some drugs can make your mouth and throat sore. You may experience:

- O redness or soreness of the gums or mouth
- O bleeding gums
- white patches on the tongue or inside the mouth
- mouth ulcers

This may cause chewing and swallowing to become more difficult. If this happens and solid foods become difficult to swallow, you may need to change their consistency or texture by having a soft or blended diet.

Keeping your mouth clean is very important. If possible, brush your teeth twice daily, floss 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.

Common mouthwashes

| Drug | General advice | How the drug is given |
|---|---|--|
| Chlorhexidine mouthwash | Use four times a day - after each meal and at bedtime. Can stain teeth. | Swish 10mls and spit. This is not to be swallowed. |
| Difflam (green colour) | Use four times a day - 30 minutes before meals and at bedtime to help your mouth feel more comfortable. | Swish 15 mls and spit. This is not to be swallowed. Difflam makes your mouth feel numb and less painful. Take care with hot food and drinks as your mouth may not feel they are too hot due to it being numbed. |
| Dispersible Aspirin tablets | Disperse one aspirin (300mg tablet) in a small amount of warm water. Use four times a day - 30 minutes before meals and at bedtime. | Swish or gargle and spit. Do not swallow. The aspirin/water mixture makes your mouth feel less painful. |
| Raspberry mucilage with dispersible Aspirin tablets (prescribed only by hospital team) | Mix 10ml of mucilage with one 300mg dispersible Aspirin tablet - dissolve in water - use four times a day. | Swish and spit. If the mucilage is used alone it can be swallowed. The mixture makes your mouth feel less painful. |
| Oxetacaine and Antacid mouthwash (prescribed only by hospital team) | Use 5-10 ml four times a day. | Swish. This can be swallowed. Take care with hot food and drinks as mouth may feel numb. |

If you have any queries about using any of these drugs please contact the Mount Vernon Hospital pharmacist (see page 2).

If you are taking **Capecitabine** tablets and develop painful mouth ulcers or swelling in your mouth, stop taking Capecitabine straight away and contact the Acute Oncology Service (see page 2).

Other publications

The Lynda Jackson Macmillan Centre at Mount Vernon Cancer Centre publishes a range of leaflets that you may find helpful:

- Appetite, loss of (HHC214)
- Chewing and swallowing problems (HHC224)
- O Constipation (managing) (HHC226)
- O Diarrhoea (managing) (HHC 227)
- Living with tiredness (fatigue) (HHC229)
- Managing taste changes (HHC244)
- O Wigs (HHC246)
- Helpful ideas to reduce wind and bloating (HHC304)

How do you feel during your SACT? - your personal record

Fill out a chart each day during each cycle of your treatment. Then bring this booklet with you when you return for your next treatment. It will help the team treating you to ease your side-effects.

This is an example of how to fill in your personal chart.

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| Best days | | | | | | | | | | | |
| Worst days | | | | | | | | | | | |

Please remember to bring this booklet with you to your next appointment

| Date: | Regimen: | Cycle no: |
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| Fill | Fill in here the dates, starting with day 1 of cycle 6 of your SACT | |
| Side-effects as they happen to you | | |
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Please remember to bring this booklet with you to your next appointment

Other help and support

People who have cancer often say that, during their illness, they experience a range of emotions. Many find it to be a stressful, anxious and confusing time.

If you have any questions or concerns about cancer and your treatment, are struggling to cope or need some support, please visit the Lynda Jackson Macmillan Centre (LJMC). Please feel free to drop in before, during or after any of your visits to the Cancer Centre.

The team at the LJMC works as part of the overall team caring for you to provide help, support and information in a relaxed setting to help you better cope with cancer and its treatment. Your family and friends are also welcome to visit the centre or call the Helpline.

A range of support services are available at the centre. These include complementary therapy, relaxation sessions, counselling and financial advice. Please ask for more details.

You do not need an appointment to visit the LJMC which is located next to the Cancer Treatment Suite by Gate 3. If you are unable to get to the LJMC, you can call the Helpline on 020 3826 2555.

Please see the back page of this leaflet for more information.

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.

| Notes: |
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Mount Vernon Cancer Centre is committed to ensuring that patients receive the best quality of care regardless of their gender identity or sexual orientation.

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 first appointment.

Identification

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

Pregnancy/fathering a child

Patients must not be pregnant or become pregnant, or father a child, during a course of treatment or for some months afterwards. **Please discuss this with your cancer specialist.**

If you are of child bearing capacity we ask that you inform a member of staff. It is our duty of care to enquire whether individuals may be pregnant or breastfeeding. This information will be kept in strict confidence.

If you think there is a chance, however small, of you or your partner being pregnant during treatment, it is extremely important that you discuss this with your oncologist, radiographer or nurse as soon as possible.

This publication has been produced by the Information team at Mount Vernon Cancer Centre. Contributors include health professionals, patients and carers who have expertise and experience in the topics covered by this publication. All our publications are reviewed and updated regularly. If you would like any details of the references used to write this information please contact the Information team on 020 3826 2555.

Questions or concerns about cancer and treatment? Need some support? Need to talk?

Drop in to the Lynda Jackson Macmillan Centre or call the support & information helpline

We will listen to your concerns, answer your questions and guide you to further information and services to help you

cancer treatment
side effects of treatment
day-to-day living with cancer
finance and benefits
counselling
someone to talk to tal
emotional support
complementary therapy
relaxation services

practical support
headwear workshops
er exercise
diet and nutrition
health and wellbeing
talking to family and friends
Look Good Feel Better
self-help courses
life after cancer

The Lynda Jackson Macmillan Centre is situated between the Cancer Centre and Gate 3 (White Hill)
Opening hours: Monday–Friday 9.30am–4.30pm
020 3826 2555
www.ljmc.org

Supporting people affected by cancer from diagnosis, through treatment and beyond



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