Author: Belinda Mills Role: Chemotherapy Nurse Practitioner Date written: July 2017 Last reviewed: May 2018 Review date: March 2021 Version: 5.6 Code: PI0602

If you need your information in another language or medium (audio, large print, etc) please contact the Customer Care Team on 0800 374208 or email: customer.care@salisbury. nhs.uk

You are entitled to a copy of any letter we write about you. Please ask if you want one when you come to the hospital.

The Friends and Family Test - Please complete The Friends and Family Test to tell us about your experience at www.salisbury.nhs.uk/FriendsFamily or download our app to your smartphone from the Apple App Store and the Google Play Store.

The evidence used in the preparation of this leaflet is available on request. Please email patient.information@salisbury.nhs.uk if you would like a reference list.

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Salisbury **Oncology**/ Haematology Service Your Personal Diary NAME. ADDRESS: E My chemotherapy regimen is called: My key worker is to Contact details - see appendix 1

Salisbury NHS Foundation Trust

#### **Emergency Contact Sheet**

## PLEASE MAKE SURE YOU HAVE A DIGITAL THERMOMETER AT HOME

If you develop any of the following while you are on chemotherapy – and for 6 weeks afterwards – you must contact your chemotherapy team/hospital for advice immediately:

- a temperature of 38°C (100.4°F) or more, or signs of infection, for example sore throat, swollen glands, stinging when passing urine or a cough
- uncontrollable chills or shivers
- sudden bruising or bleeding
- uncontrollable vomiting
- uncontrollable diarrhoea
- any sudden shortness of breath or difficulty breathing
- any sudden chest pains (call for an ambulance 999)
- any sudden pains or swelling in your legs (or arms if you have a peripherally inserted central catheter -PICC)
- redness or discharge around your Groshong line or PICC
- shivering episodes after flushing your Groshong line or PICC
- pain or swelling in your stomach
- persistent headaches
- seizures
- excessive thirst.

#### Notes

#### DON'T DELAY

It is important you act straight away and call us.

24 hour Hotline number – 01722 341930

When you call the nurse will want to know:

- your name
- your chemotherapy regimen
- the date you last had treatment
- your temperature
  - when and if you have taken paracetamol recently
- your symptoms and when they started.
- or
- Your concerns or queries.

For other key contacts please see appendix 1.

#### Notes to hospital staff – A&E, AMU

PLEASE CONTACT THE ON CALL HAEMATOLOGIST IF YOU SUSPECT NEUTROPENIC SEPSIS – (sepsis is a very severe infection and can be life-threatening).

Follow the Neutropenic Care Pathway, available on ICID, in A&E, AMU and Pembroke Unit.

Contact the Acute Oncology team – bleep 1480 for advice and guidance with this patient's care.

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| Bowel Cancer UK                         | Freephone:<br>0800 840 3540              | www.bowelcanceruk.org.uk   |
|---|--|----------------------------|
| British Lung Foundation                 | Freephone:<br>03000 030 555              | www.lunguk.org             |
| Prostate Cancer UK                      | Freephone:<br>0800 074 8383              | www.prostate-cancer.org.uk |
| Ovarian Cancer UK                       | Freephone:<br>0845 371 0554              | www.ovacome.org.uk         |
| Cancer of Unknown Primary<br>Foundation | contact via email on<br>their website    | www.cupfoundjo.org         |
| Cancer Research UK                      | 0808 800 4040                            | www.canceresearchuk.org    |
| Specialist Nurses                       |  |                            |
| Breast care nurses                      | 01722 336262 ext. 59<br>or 5910          | 13 Bleep 1622              |
| Colorectal nurse                        | 01722 336262 ext. 21                     | 94 Bleep 1239              |
| Upper gastrointestinal nurse            | 01722 336262 ext. 21                     | 94 Bleep 1457              |
| Stoma care                              | 01722 336262 ext. 42                     | 56 Bleep 1694 or 2045      |
| Lung nurse                              | 01722 336262 ext. 24                     | 97 Bleep 1092              |
| Haematology nurse                       | 01722 336262 ext. 46                     | 91 Bleep 2044              |
| Gynaecology nurse                       | 01722 336262 ext. 44                     | 31 Bleep 3127              |
| Urology nurses                          | 01722 336262 ext. 48                     | 66 Bleep 1692              |
| Acute oncology team                     | 01722 425257                             | Bleep 1480                 |
| Advanced nurse practitioner             | 01722 345578<br>(answerphone)            | Bleep 1479                 |
| Research nurses                         | 01722 336262 ext.<br>4191/4129/2103/4459 | )                          |
| Macmillan Nurse Specialist              | 01722 425137                             |                            |

I

| Other - contacts  |                                       |                             |     |
|---|---------------------------------------|-----------------------------|-----|
| Pembroke unit contac  | ct details                            |                             |     |
| <ul> <li>Oncology Outpat</li> </ul>                             | tients (e.g. appo                     | vintments)                  |     |
| 01722 336262 ex   | kt. 4382 Mon - F                      | ri, 9am - 5pm               |     |
| Pembroke Suite  | (other non-urge                       | nt advice)                  | Gen |
|   | · ·                                   | Mon - Fri, 8.30am -         |     |
| Pembroke ward   | (for out-of-hours                     | advice)                     |     |
| 01722 336262 ex   | xt. 5070                              |                             |     |
| • · · _ = • • • • - • - •                                       |                                       |                             |     |
| National contac   | cts                                   |                             |     |
| Leukaemia Care (all<br>haematology conditions)                  | Freephone:<br>0800 010 444            | www.leukaemiacare.org.uk    |     |
| Lymphoma Association  | Freephone:<br>08 08 808 5555          | www.lymphoma.org.uk         |     |
| International Myeloma<br>Foundation UK                          | Freephone:<br>0800 980 3332           | www.myeloma.org.uk          | SEC |
| Aplastic Anaemia Trust (aplastic<br>anaemia and myelodysplasia) | Local rate helpline:<br>0870 487 7778 | www.theaat.org.uk           |     |
| Cancerhelp uk   | Freephone:<br>0800 800 4040           | www.cancerhelp.org.uk       |     |
| Macmillan Cancer Support  | Freephone:<br>0808 808 0000           | www.macmillan.org.uk        |     |
| Breastcancer care   | Freephone:<br>0808 800 6000           | www.breastcancercare.org.uk |     |
| Lavender Trust (breast cancer care fund raising)                | Freephone:<br>0808 800 6000           | www.lavendertrust.org.uk    |     |
| Pancreatic Cancer UK  | 020 3535 7099                         | www.pancreaticcancer.org.uk |     |

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#### Chemotherapy side effect diary

#### **CIRCLE THE APPROPRIATE COLUMN AND FILL IN DATES**

CYCLE NO. \_\_\_\_\_ DATE GIVEN \_\_\_\_\_

| Туре                                   | Mild   | Moderate  | Severe  | Start date | Stop date |
|--|--|---|---|------------|-----------|
| Temperature                            | T< 38° but<br>not NML                                    | T≥ 38° or<br>chills T≥ 38° Wit<br>chills  |   |            |           |
| Energy level fatigue                   | Symptoms<br>but NML<br>activity                          | Rest < ½ of<br>each day   | Rest ≥ ½ of<br>day; unable<br>to leave bed        |            |           |
| Nausea /<br>appetite                   | <ul> <li>→ appetite<br/>eating ½ of<br/>meals</li> </ul> | Vomiting<br>1-2 x/day;<br>eating< ½ of<br>meals                                   | Unable to<br>eat anything<br>vomiting ><br>2x/day |            |           |
| Mouth                                  | Tender & red<br>gums                                     | 1-2 ulcers;<br>pain with<br>eating /<br>swallowing                                | >2 ulcers;<br>taking<br>liquids only              |            |           |
| Constipation                           | Hard stool<br>or ≤ 2 days<br>since BM                    | <ul> <li>→ appetite;</li> <li>≥ 3 days</li> <li>+straining</li> <li>BM</li> </ul> | ≥ 3 days  |            |           |
| Diarrhoea                              | Loose; ≤ 1-2<br>/day                                     | 3-6/day; at 7-9/day;<br>night and/or incontinent<br>with cramps                   |   |            |           |
| Nerves/<br>weakness                    | Occ. tingling<br>able to<br>perform ADL                  | Severe<br>T/N; or mild<br>weakness<br>Diff. to walk                               | T/N; or mild T/N; marked weakness weakness        |            |           |
| Pain (scale<br>1=no pain<br>10=severe) | 1-3;<br>relieved by<br>medicine                          | 4-6;<br>unrelieved<br>w/ medicine   | 7-10;<br>keeps you<br>awake                       |            |           |
| Hands/feet                             | Painless but<br>red palms                                | Painful and/<br>or itching;<br>red  | Blisters or<br>cracking                           |            |           |
| Hydration                              | No more<br>than 1.5L/<br>day                             | Drinking ≤ 1<br>litre /day  | Unable to<br>drink                                |            |           |
| Sleep                                  | Occ.<br>drowsiness                                       | Fall asleep in Unable to conversation stay awake                                  |   |            |           |
| Skin                                   | Dry; needs<br>added<br>moisture                          | Flaking ; Peels/cracks<br>itches w/<br>redness                                    |   |            |           |

Please contact Pembroke Unit for any complaint within the red

columns

#### Chemotherapy side effect diary

#### **CIRCLE THE APPROPRIATE COLUMN AND FILL IN DATES**

CYCLE NO. \_\_\_\_\_ DATE GIVEN \_\_\_\_\_

| Туре                                   | Mild   | Moderate  | Severe  | Start date | Stop date |
|--|--|---|---|------------|-----------|
| Temperature                            | T< 38° but<br>not NML                                    | T≥ 38° or T≥ 38° With chills  |   |            |           |
| Energy level<br>fatigue                | Symptoms<br>but NML<br>activity                          | Rest < ½ of<br>each day   | Rest ≥ ½ of<br>day; unable<br>to leave bed        |            |           |
| Nausea /<br>appetite                   | <ul> <li>→ appetite<br/>eating ½ of<br/>meals</li> </ul> | Vomiting<br>1-2 x/day;<br>eating< ½ of<br>meals                                   | Unable to<br>eat anything<br>vomiting ><br>2x/day |            |           |
| Mouth                                  | Tender & red<br>gums                                     | 1-2 ulcers;<br>pain with<br>eating /<br>swallowing                                | >2 ulcers;<br>taking<br>liquids only              |            |           |
| Constipation                           | Hard stool<br>or ≤ 2 days<br>since BM                    | <ul> <li>→ appetite;</li> <li>≥ 3 days</li> <li>+straining</li> <li>BM</li> </ul> | Bloated; ><br>4 days BM;<br>vomiting              |            |           |
| Diarrhoea                              | Loose; ≤ 1-2<br>/day                                     | 3-6/day; at<br>night and/or<br>with cramps  |   |            |           |
| Nerves/<br>weakness                    | Occ. tingling<br>able to<br>perform ADL                  | Severe Intolerable<br>T/N; or mild<br>weakness<br>Diff. to walk                   |   |            |           |
| Pain (scale<br>1=no pain<br>10=severe) | 1-3;<br>relieved by<br>medicine                          | 4-6;<br>unrelieved<br>w/ medicine   | 7-10;<br>keeps you<br>awake                       |            |           |
| Hands/feet                             | Painless but<br>red palms                                | Painful and/<br>or itching;<br>red  | Blisters or<br>cracking                           |            |           |
| Hydration                              | No more<br>than 1.5L/<br>day                             | Drinking ≤ 1<br>litre /day  | Unable to<br>drink                                |            |           |
| Sleep                                  | Occ.<br>drowsiness                                       | Fall asleep in conversation   | Unable to stay awake                              |            |           |
| Skin                                   | Dry; needs<br>added<br>moisture                          | Flaking ;<br>itches w/<br>redness   | Peels/cracks                                      |            |           |

Please contact Pembroke Unit for any complaint within the red columns

## SECTION ONE

#### Your personal record

This personal record is to help you to understand your illness and treatment.

Both you and your medical team should make entries. We hope this will improve communication between everyone involved in your care. However, this record does not replace medical or nursing records, and you need only use it if you find it helpful.

Please bring this record with you to all your appointments, such as X-ray, GP, out-patients.

Additional information about your illness and treatment can be added to this booklet. If you would like further information please ask your nurse or doctor.

You may have questions or concerns that are not explained in this pack. If so please do not hesitate to ask the doctor or nurse caring for you.

## Appointments/calendar

After a course of chemotherapy treatment, your nurse or doctor will arrange for a follow-up visit which will depend on the length of your treatment.

The following page will allow you to keep a note of your next appointment(s).

Some patients may have a follow-up appointment with their consultant in places other than the Pembroke Suite. This appointment may be sent to you in the post. A nurse will advise you.

# Description of abbreviations used in chemotherapy side effect diary

Below is an explanation of the abbreviations used throughout the chemotherapy side effect diary. Please speak to the nurse if you need more information.

| Т     | = temperature                                    |
|-------|--|
| NML   | = normal   |
| Х/    | = times per                                      |
| BM    | = bowel movement                                 |
| Occ.  | = occasional                                     |
| T/N   | = tingling and/or numbness                       |
| ADL   | = activities of daily living (dressing, bathing) |
| Diff. | = difficult                                      |
| w/    | = with   |
| L     | = litre of fluids                                |
| add.  | = additional                                     |
| <     | = less than                                      |
| >     | = more than                                      |
| ▼     | = decreased or reduced                           |
|       | = increased                                      |
| ≥     | = equal to or more than                          |
|       |  |

 $\leq$  = equal to or less than

## Chemotherapy side effect diary

The following diary is provided for your personal use to help monitor your individual side effects. Please keep this diary up to date and bring it with you to all of your appointments.

#### INSTRUCTIONS FOR FILLING IN:

- 1. At the top of each page, fill in the date you received treatment and the cycle number beginning with No.1
- 2. If you experience any of the side effects listed under TYPE, circle the appropriate column that matches with the level of your symptom
- 3. Fill in the date the side effect started and ended in the last two columns
- 4. If the severity of the side effect is listed under moderate or severe,

call the Pembroke Suite (Mon.- Fri. 8:30am - 4:30pm) or the Pembroke Ward (out-of-hours or weekends) (see Appendix 1 for telephone numbers)

You will be told by oncology-trained personnel how to deal with your side effects. Please do not try to deal with side effects without advice.

If you need additional diary sheets, please tell your nurse at your next clinic visit.

A description of abbreviations used in the following diary can be found on the next page.

## **Appointments**

| Date | Time | Consultant and place and reason |
|------|------|---------------------------------|
|      |      | for appointment                 |
|      |      |                                 |
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| Date | Time | Consultant and place and reason for appointment |
|------|------|---|
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The side effects from radiation therapy can be well managed and will disappear gradually after your treatment is over. The radiation oncology department will have a fully qualified team of doctors, nurses, and radiographers to help you deal with any side effects from your radiation therapy. Please ask your oncology nurse for further information about radiation therapy and he/she will give you a booklet with more detailed information.

## Follow-up plan

Each person will have an individual follow up plan based on their state of health and type of cancer.

At the end of treatment you may need to have some of same scans and tests you had when you were first diagnosed. This is to find out how well the chemotherapy has worked.

Some people may be taking part in clinical trials which have specific follow-up schedules. Others may be seeing a doctor in another treatment area before commencing follow-up.

Your doctor should discuss your individual follow-up treatment plan with you.

This booklet has been designed by your haematology/ oncology team to provide you with information about your disease and treatment plan. It is our aim to provide you with full support and management throughout your time with us. If you feel at any time that you need more information and/or support, please feel free to contact any member of the team for additional information.

We have a large amount of free information available in the waiting room of Pembroke Suite. Also you may wish to refer to the *Other Useful Contacts* in Appendix 1.

Some people may finish their treatment after chemotherapy, while others may be going on to a secondary type of treatment or may need additional treatment for support and symptom management. Again, this new phase in your cancer journey may be stressful because it causes change.

#### Radiotherapy

Radiotherapy is always given at specialist cancer centres. These centres are at Southampton, Poole and Bath. The place depends on where the patient lives.

Some people with cancer may be having radiotherapy, either as a single type of treatment or in combination with other treatments such as chemotherapy or surgery. Radiation therapy is the use of x-rays and/or similar rays to destroy cancer cells in a specific treated area. It can be given either externally or internally. It targets a specific area such as the breast, prostate or bone. Radiation therapy may be used to cure cancer, to control tumour size, to reduce the chance of cancer coming back in a specific location or as an addition to other treatments to reduce cancer symptoms.

If you are continuing on to radiation therapy your oncologist will be discussing your particular treatment plan with the radiation oncology department where you will be receiving your treatment. Generally speaking, external radiation therapy is given Monday - Friday for a certain number of weeks. Each person will have a different dose and duration of treatment. Other telephone numbers for quick reference:

GP phone number \_\_\_\_\_ District nurse number Other useful numbers Specialist nurse numbers My Allergies: ..... ..... ..... .....

## SECTION TWO

## **Pembroke Unit Introduction**

The Pembroke Unit is made up of four areas: The Pembroke Suite, the Pembroke Ward, the Oncology/Pathology outpatients and the Mobile Cancer Care Unit.

## The Oncology/Pathology outpatients

Your first and subsequent appointments are mostly held in these clinics where you will see your oncologist, haematologist and/or members of the team. Appointments are held here, Mon - Fri 9am - 5pm.

#### The Pembroke Suite

The Pembroke Suite is a day Oncology/Haematology service. It is open:

Monday to Friday 8.30am to 6.30pm

for telephone advice, information and support for all patients and their carers and relatives.

There are different haematology and oncology consultants who specialise in different types of cancer or haematology conditions. You will have been referred to one of these consultants according to your diagnosis.

The Suite has a small team of friendly nursing and support staff who specialise in caring for patients with cancer and blood conditions. They work closely with other members of multi-disciplinary teams, breast-care nurses, colorectal nurse specialist, lung cancer nurse specialist, palliative care nurses, urology nurses and also your own GP and district nursing staff.

## **SECTION SIX**

## Transitions

Treatment for cancer can be difficult. You have been facing physical, psychological, social and often financial struggles since the day of your diagnosis of cancer. You may feel as if you had one life 'before cancer' and another life 'after cancer'. Adjusting to life after cancer treatment takes time. It is a process and not a certain fixed point with a beginning and end. It will not happen overnight and you may have a feeling of being in 'limbo' while you regain your physical strength, learn to trust your body again, and resume your 'normal' family and social roles and relationships.

Many people experience lots of mixed emotions: a mixture of joy and fear, anxiety and relief, security and uncertainty. These feelings are normal. There are additional support groups you may find helpful at this time. References for these can be found in section 5 of this booklet under ' Personal Support'.

After finishing their treatment many people expect to be able to return to work straight away, or resume their previous physical activity at the same level. Their family, friends, and employers may feel the same way. However, everyone responds differently and takes different lengths of time to heal. Some people may feel tired for up to a year following their treatment. Looking after yourself at this time, not pushing yourself or pretending to others that you are 'fine now' is very important. This process of healing and adjustment will allow you, your family, friends, and loved ones, gradually to create a new normal.



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#### Travel insurance companies

Once diagnosed with cancer obtaining travel insurance may become more challenging and more expensive. Please discuss with your consultant if you wish to go on holiday during your chemotherapy treatment.

There are two Macmillan Travel Insurance leaflets available which contains some very helpful information. Please ask one of the nursing staff.

## Free prescriptions

From the 1st April 2009 all patients receiving treatment for cancer, the effects of cancer, or the effects of current or previous cancers are entitled to free prescriptions. You only need to apply for a certificate if you normally have to pay for prescriptions.

The certificate lasts for 5 years and is valid for every NHS prescription that you receive during those 5 years.

To apply for a certificate you need to complete an application form (Form FP92A). This can be obtained from your GP or consultant at the hospital. It provides information and advice on the following:

- advice about benefits and grants
- support group advice and Specialist care
- written advice and one-to-one nurse advice about your condition or treatment process
- referral to a district nurse or the MacMillan Nurse for additional support during treatment.
- · dietary advice and referral to a dietician
- transport service
- hair clinic
- emergency advice related to complications of treatment or disease.

## The Pembroke Ward

Is a ten-bedded inpatient area. Patients are admitted for different reasons, for example longer chemotherapy treatments and symptom control.

Pembroke Ward offers urgent 24-hour telephone advice.

## Mobile Cancer Care Unit (MCCU)

The Mobile Cancer Care Unit is a purpose-built vehicle on which chemotherapy nurses from the Pembroke Unit at Salisbury NHS Foundation Trust give chemotherapy and other supportive treatments. It is supported by the national cancer charity 'Hope for Tomorrow'. The MCCU travels from Salisbury to locations within the Salisbury NHS Foundation Trust catchment area in Wiltshire, West Hampshire and Dorset.

## The Pembroke Unit Philosophy

The unit offers multi-disciplinary patient care which includes medical staff, specialist nurses, dieticians, the palliative care team, social workers and community services.

We aim to provide an efficient service with a high standard of care for patients with oncology and haematology disorders who are receiving conventional, innovative or complementary treatments.

The nursing staff value the privacy and dignity of all individuals, and will always maintain confidentiality.

Every patient has the right to discuss diagnosis and treatment, and will have opportunities to make informed choices in a quiet and relaxed environment.

Patients' religious, spiritual and cultural beliefs and preferences will be respected at all times.

Nursing care that is researched and evidence based will be delivered to the highest standard in accordance with professional codes of conduct, Salisbury NHS Foundation Trust policies and the NHS Constitution.

## **Treatment process**

Before starting a course of chemotherapy and/or radiotherapy treatment, the consultant will discuss this with you. It may be a good time for you to ask questions. Each patient is different; receiving a different course of treatment. It is a good idea to have a member of your family or a close friend with you. They will often think of questions to ask that you haven't thought of.

## How can we help

It is our policy to work together with you and your family to ensure we check your entitlement to any state and local benefits. We will advise you about all of your options, assist with any correspondence and we will help you complete any claim forms.

It is YOUR CHOICE if and when you see the adviser. You could see her in the hospital or at one of our Outreach offices.

#### How to contact us

We can be contacted Mon – Fri by telephone 01722 441393; if we are out of the office please leave us a message on our answer machine.

We WILL return your call as soon as possible

or

You can email us on: macmillan@citizensadvicewilthire.org.uk or

You can ask your Cancer Nurse Specialist to make the referral. Ask the nursing staff if you need help with any of the above; we can also give you advice about the following:

- transport costs/claim forms, disabled badge
- pre-payment prescriptions
- entitlements, free NHS prescriptions, dental treatment, sight tests.

we will explain as much as possible

The Palliative Care Service aims to support the patient and family wherever they are. There are five branches of the service:

- Community Palliative Care Team
- Hospital Palliative Care Team
- Peter Gillam Support Centre
- Inpatient Unit (Hospice)
- Social Work and Bereavement Service.

Separate leaflets are available from the Palliative Care team giving more details about each branch of the service.

All of these services are based at Salisbury Hospice which is a purpose-built building on the Salisbury District Hospital site.

The Palliative Care team will visit you and assess your needs and plan with you how best to help you and your family. Palliative Care staff always liaise closely with your medical and nursing teams in the community and in the hospital.

If you would like more information telephone the secretary on 01722 425113.

## **Financial support**

We are Salisbury and District Citizens Advice Bureau working in partnership with Macmillan Cancer Support who together have established a specialist benefits/money advice service for people and their families affected by cancer.

## **Pre-Assessment clinic**

You will be given written information about your treatment. You will also have an opportunity to attend a chemotherapy pre-assessment clinic before starting your chemotherapy treatment, to learn more about the associated side-effects of your treatment. This is an opportunity to look at other support we can put in place to help you through your treatment. Again, it is helpful to have someone with you if you wish.

We will also ensure you have had any investigations needed prior to starting treatment and ask you to sign a consent form. If you require more information please ask us; at every visit you will always have the chance to ask more questions about your disease and treatment.

#### **On-going treatment review**

Each cycle of chemotherapy will be prescribed by a consultant or a non-medical prescriber. You will require a blood test before each cycle of chemotherapy, unless you have been told it will not be necessary. Please attend the blood-testing department first (Pathology level 3) before you go to the Pembroke Suite. If you have a Groshong or PICC catheter you will be told where to go to have blood taken.

Before starting your treatment, your consultant may decide you need x-rays, scans, or other investigations. Each test and the reason for having it will be explained. You may also need tests between cycles of treatments, and/or at the end of treatment.

On the second and subsequent treatments you will see the consultant or nurse practitioner for a consultation, and unless your treatment is just tablets your treatment is likely to be given a day or two later. This allows the pharmacy time to prepare your treatment.

Section 3 describes this further.

## SECTION THREE

## Treatment

This part of the booklet provides you, your relatives and carers with information about your condition and the course of treatment. The consultant and nurse will discuss your treatment with you before it starts. Please use the space provided in the diary to write any notes or questions you may have before your appointment, so that you can remember them.

#### What is cancer?

This is a general term used for a number of different diseases caused by the uncontrolled growth of cells. Cancers are named according to the cells from which they grow. Cancers are constantly dividing; this is important as one mode of action of chemotherapy works on cells that are dividing.

The area of the body in which a cancer starts is called the primary site; if the cancer spreads these are known as metastases.

## Palliative care

Palliative care aims to support patients and their families who are coping with the effects of a serious illness by controlling symptoms and giving practical advice to help them manage more easily at home.

The palliative care team work with doctors and nurses in the hospital and with GPs and district nurses when care is needed at home.

We can give you information about:

- promoting quality of life being able to do what is important to you
- managing pain or discomfort
- mouthcare
- tiredness
- managing independently at home
- grants and financial assistance
- coping with niggling worries, anxiety or low moods
- constipation
- loss of appetite, feeling sick.

Our aim is to help you enjoy life as much as possible whilst living with your illness.

Quality of life is unique to you. What makes you feel good and enjoy life may be very different from the next person's needs.

Quality of life also includes quality of treatment. We want to give you care that is appropriate for you. You need to know what choices are available – do not hesitate to ask questions;

If you wish, the massage sequence can be shown to your relatives/carers to enable you to continue your relaxation at home. You can buy tailor-made products for your home use; please consult your therapist.

#### Aromasticks

Aromatherapy is used on the Pembroke Suite to help with anticipatory nausea and vomiting (ANV). Aromasticks are available as an alternative smell that may help decrease your anxiety and keep you from feeling sick. You will be given 5 different aromasticks (labelled 1 to 5) to use in rotation each time you come for chemotherapy, so that you don't learn to associate a particular smell with your treatment. All the essential oils have been chosen because they help with either nausea or relaxation. If you would like to try aromatherapy to help with your ANV please ask your nurse for a pack.

Complementary therapies on the Pembroke Unit are funded at present by patients' fund-raising efforts and donations to the ward funds. Therefore you will not be asked to pay should you wish to receive complementary therapies during your time on the unit.

#### **Useful contacts**

International Federation of Professional Aromatherapists 82 Ashby Road, Hinckley, Leicestershire, LE10 1SE

Penny Brohn UK Chapel Pill Lane, Pill, Bristol, BS20 0HH www.pennybrohn.org.uk

## What is chemotherapy?

Chemotherapy simply means treatment with drugs. These drugs can be given by mouth (oral), injection into the skin (subcutaneous) or injection into a vein (intravenous).

The term chemotherapy is used generically throughout this diary, whether it is cytotoxic chemotherapy or targeted therapies, such as immunotherapies.

Some patients have treatment through a PICC or STCVC (see page 19). This is an alternative way to receive treatment. There are two main reasons why you may need one of these lines:

- your treatment may require it
- you may have small or fragile veins.

A STCVC is inserted centrally under X-ray control, with a tube leading into a vein to your heart. A PICC is put into a vein in your arm (carried out by a specialist nurse or radiologist on the Pembroke unit or in radiology). If either of these options are suitable for you, your consultant/nurse will discuss it with you. You will also be given written information about this.

Cytotoxic chemotherapy literally means toxic to cells.

A nurse will discuss the possible side effects with you at the Pre-Assessment Clinic and on the day of your first treatment.

Normal cells repair themselves, but cancer cells cannot. When cytotoxic therapy is given it is followed by a rest period. This allows the normal cells and you to recover.

Every treatment depends on the type and stage of your cancer.

At Salisbury we are involved in research trials. Your consultant will discuss this with you if there is a clinical trial suitable for you. See page 26 about clinical trials.

Thanks to research and what we understand about certain cancers there are different groups of drugs which are used to treat cancer. They have different ways of killing the cancer cell and are described below. It may be that your chemotherapy regimen includes one of these drugs and your consultant and nurse will discuss this with you.

#### **Targeted Therapies**

Researchers are increasingly looking at therapies which target cancer cells more specifically. There are several types of newer treatments including monoclonal antibodies, cancer growth inhibitors, immunotherapies, vaccines and gene therapy. Each of these therapies is usually only specific to one cancer, but not exclusively.

More and more of these drugs are being used to fight cancer. The side effects and benefits will be discussed with you.

#### Hormones

Hormonal therapies work by altering the production or activity of particular hormones in the body. They are most commonly used to treat breast cancer and prostate cancer. The type of hormone therapy given depends on the type of cancer being treated. The aims of complementary therapies on the Pembroke Unit are:

- encourage relaxation and a sense of calm
- encourage a sense of well-being
- help reduce physical pain
- ease discomforts such as nausea, poor sleep, vein pain, dry skin
- encourage a positive body image.

#### "It's amazing how relaxing it is just having your hands done"

The therapies on offer on the Pembroke Unit include the following:

- aromatherapy hand or foot massage
- hand or foot massage (without essential oils)
- aromasticks for anticipatory nausea and vomiting.

#### Aromatherapy and massage

Aromatherapy is an accepted branch of complementary therapy; it uses essential oils extracted from aromatic plants. The therapist will advise you in your choice of oils for your hand or foot massage; it is important that you like the fragrance and you will be asked which oils you prefer.

During your treatment your sense of smell may be more sensitive and you may prefer not to have essential oils, in which case you could have a hand or foot massage with fragrance-free grape-seed oil.

## Information for relatives and friends

Your illness may affect your family and friends. You may like to share the information you have received with them.

It will be helpful if close family or friends know the effects of chemotherapy on your blood and what action to take if you get a temperature and infection.

Family and friends often want to help and support you. You may find it useful to have practical help with shopping, housework, visits to the hospital or collecting the children from school. You could ask one person to co-ordinate help and telephone calls to see how you are doing.

Don't be afraid to identify times when you want quiet time or days when you may not feel well enough for visits or phone calls. If you are feeling isolated or finding it difficult to cope, talk to the nursing staff so that professional support can be organised if necessary.

## **Complementary therapies**

During your treatment time on the Pembroke Unit you may be offered complementary therapies.

Complementary therapies are offered in many cancer hospitals and treatment centres across the UK alongside conventional medicine. Your doctors at Salisbury District Hospital are aware of and support the use of complementary therapy on Pembroke Unit.

Alternative therapies are not complementary therapies; they are used instead of conventional medicine, may have unpleasant side effects and are not recommended by Salisbury District Hospital staff.

#### Monoclonal antibodies

One of the ways we fight infection is to make antibodies. They help our immune system to recognise an infection if we are exposed to it again, and to enable our body to deal with it quickly. Antibodies can be made in a laboratory and used to treat cancer.

Monoclonal antibodies (called this because they come from a single cell) work by recognising the protein on the surface of the cancer cell and then locking onto it (like a key in a lock). They destroy the cancer by either:

- triggering the body's immune system to attack the cancer cell and can cause the cell to kill itself, or
- attaching a cancer drug or a radioactive substance to the antibody which delivers them directly to the cancer cell because they target those specific cells (targeted therapy).

#### Cancer growth inhibitors

In order to grow and divide cancer cells 'communicate' with each other using chemical signals. Cancer growth inhibitors interfere with this process and so affect the cancer's ability to develop.

#### Angiogenesis inhibitors

For tumours to survive they need to produce a network of blood vessels; angiogenesis inhibitors interfere with the development of blood vessels. This means that the cancer is unable to receive the oxygen and nutrients it needs to survive.

# Stem cell or bone marrow transplant (haematology conditions)

Before starting this treatment it will be fully discussed with you by the team. You will be given written and verbal information. This section in the diary is to give you some understanding of what the treatment means to you.

A blood stem cell or bone marrow transplant is a procedure which allows some patients with haematology conditions to have much higher doses of chemotherapy (and sometimes radiotherapy) than usual. The procedure aims either to extend the period of remission or to improve the chances of a cure. The chemotherapy will cause long-term bone marrow suppression, so after the chemotherapy an infusion of stem cells are given.

These are the cells in the bone marrow responsible for the production of all blood cells. They can be collected from either the patient or a compatible donor.

If your own stem cells are used, the transplant is known as an autologous transplant, or autograft. The stem cells are usually collected from your blood about 2 to 3 weeks before the transplant, this is called the harvest. For an autograft the cells are then given back to you at Southampton Hospital. Your recovery will then be in Salisbury.

If donor stem cells are used the transplant is known as an allogeneic transplant, or allograft. This sort of transplant will usually take place in Southampton. The stem cells are collected from the donor on the day of the transplant.

## **Spiritual support**

People can also find that spiritual support is helpful and if you have a faith that you follow you may want to talk to your spiritual leader.

The hospital has a chaplaincy team who are happy to speak or meet with you and can be contacted on 01722 336262 ext 4271. If you wish to speak to someone of your own faith, the Chaplaincy Team are happy to contact them for you.

## **Psychological distress**

Up to half of people who have cancer will suffer from clinical depression or anxiety at some time during their illness. Cancer can also cause problems with relationships, body image, and other distressing psychological effects. Often, these can be so severe that they interfere with daily life or treatment programme. At Salisbury we have a Psychological Support Team on site that can provide support for psychological distress.

If you feel that you or a member of your family would like to talk to a member of the Psychological Support Team, please discuss this with a member of your medical team. They can then refer you for support. If your thoughts and feelings are affecting your life or treatment then the Psychological Support Team may be able to help. Appointments are usually offered within two to three weeks of referral and are held at the hospital.

This service is completely confidential.

## SECTION FIVE

## **Personal Support**

## Emotional and social support

Each patient will be cared for in a 'holistic' manner whilst on the Pembroke Unit. This means that the staff will treat not just the 'disease' but will talk to you about other things as well and if required can offer you:

- help with emotional needs
- help with social problems
- help with financial problems.

The staff can also, with your consent, refer you to a nurse specialist or the palliative care nursing service for pain or symptom control. The dietician can also be contacted for any help or advice you might need.

They can contact the district nurse for follow-up care for Groshong and PICC.

If required they can refer you to Social Services; this would also need your consent.

Social Services can help in a variety of way such as, support for you at home and staying safe. Some people may need advice/support about residential care. A stem cell transplant requires you to be an inpatient for at least 3 weeks, during which time you can become very unwell. If you are to have this treatment it will be fully discussed with you by your consultant and the haematology nurse specialist many weeks beforehand.

## **Treatment protocols**

Each patient is cared for according to his or her needs and treatment.

The staff aim to give clear and to the point information about the treatment you will be receiving.

The staff will answer any questions or concerns you may have about your treatment. You will have an initial consultation with the doctor, then with the nurse who will explain the treatment in more detail.

Before each cycle of treatment most patients need a blood test. Either the nurse or the doctor will give you a form for this.

The blood test allows us to make sure that your body is coping with the treatment and that the blood cells are returning to their normal level. Sometimes for one reason or another (e.g blood count to low) we need to delay your treatment. We need to ensure it is safe to proceed with the treatment. We will explain our decision for delaying your treatment to you.

## **Clinical trials**

At Salisbury District Hospital we take an active role in cancer research studies. By participating in clinical trials we hope to find new and better ways of preventing, diagnosing or treating cancer. Most of the treatments available today have previously been tested in trials. As one of your treatment options you may be invited to take part in a trial. If you are willing to consider this, your doctor and research nurse will discuss it with you and will give you written information about it. You will be given enough time to think about it and to discuss it with your friends, family or GP if you wish. It is important to understand that the trial may not directly benefit you, but will help to decide the best treatment for future patients.

You should only agree to take part if you are happy with what is being asked of you. Make sure that you have had all your questions answered and understand what is involved. This will include the possible risks as well as the benefits. When you are sure you understand and if you wish to take part in the trial, you will be asked to sign a consent form.

If you choose not to take part in the trial your care will not be affected in any way. You will receive the standard treatment. If you sign a consent form you will still remain free to withdraw at any time, if you change your mind. This will not affect how you are treated in the future.

If you are taking part in a trial you will be closely and regularly monitored. Any information collected about you will be kept strictly confidential and will comply with the 1998 Data Protection Act. having cancer and receiving chemotherapy. No one reaction is the 'right' or 'wrong' one.

A partner's concerns or fears can also affect the sexual relationship. Communication becomes so important at this time. If you are having difficulty expressing your feelings or concerns, please ask your doctor or nurse for advice, or referral to someone who can help you to communicate more openly.

While your body may be going through many physical and emotional changes right now, if you were comfortable with and enjoyed sexual relations before starting your treatment, you can continue to enjoy them.

You may find out this is a time for discovering new ways of expressing intimacy and sexual feelings. It is up to you and your partner to find out together what is pleasurable and satisfying to you both. If you would like any additional information or booklets specific to sexuality and cancer, please ask your clinic for free booklets published by Macmillan Cancer Support.

Remember, the changes to your sex life don't usually last long. There is no medical reason to stop having sex during chemotherapy. The drugs won't have any long-term effects on your performance or enjoyment of sex. Cancer can't be passed on to your partner during sex

## Men

Receiving chemotherapy can cause temporary or permanent infertility. Infertility affects a man's ability to father a child but does not affect his ability to have sexual intercourse.

It is important to discuss this issue with your doctor before you begin chemotherapy if you think you might wish to consider sperm banking (a procedure that freezes sperm for future use).

Men having chemotherapy should use an effective means of birth control with their partners during treatment. This is to prevent the harmful birth defects that could occur if their partner becomes pregnant. Ask your doctor when you can stop using birth control for this purpose.

Some men may experience difficulty or an inability to maintain an erection especially after being treated for prostate or bowel cancers. This is because of possible nerve damage. Often this is temporary and will improve with time.

Don't give up if you notice initial changes. Talk to your doctor for advice. Also, talk about these problems with your partner to avoid frustration, guilt, and/or anger from either partner. Many individuals do adjust and with professional help and advice resume a satisfying sex life.

## Sexuality

Sexual feelings and attitudes vary greatly between individuals normally, and particularly during chemotherapy. Some people may have an increased desire for intimacy and sexual activity once diagnosed with cancer. Others find that their sexual desire decreases, along with their energy level because of the medications they are taking. Some people find that their sexual desires decline due to the physical and emotional stresses of

#### Questions you might wish to ask:

- what is the purpose of the trial?
- what are the alternatives?
- what potential benefit is there for me and for future patients?
- what are the possible side effects of the treatment?
- will I need to have any additional hospital appointments?
- what extra tests will I have?
- who can I contact if I need any further information?
- if I have a problem, will someone be available 24 hours a day?
- what will happen if I wish to stop the treatment?

#### For further information please contact:

#### The Cancer research office

Julie Atlee – 01722 429191 Catherine Reed – 01722 429191 Sarah Salisbury - 01722 336262 ext 2103 Vicky King - 01722 336262 ext 4459

#### Who gives your treatment

Your treatment will be given to you by an experienced nurse with a specialist knowledge of cancer, chemotherapy, symptom control and support advice. They also have counselling and support skills to provide a high standard of treatment and care for you and your family. On the day of treatment, you may be offered either a chair or a bed. Pembroke Suite is a day-care service therefore you can go home when you have finished your treatment. The consultant or nurse will advise you if your treatment is changed.

Lunch and other refreshments are provided on the unit, but please eat and drink as normal prior to starting your treatment.

Please continue to take any medication as usual unless instructed otherwise by your consultant or nurse.

Ensure that we are aware of any medication you are taking, so we can check for any interactions these may have with your treatment.

## Driving

We do not advise you drive on your first treatment day in case you do not feel well or you have had a drug which may alter your concentration. You may find that after your first treatment you feel well enough to drive for your remaining appointments.

We can book hospital transport for you, but we need at least two days' notice. You may bring a family member or a friend with you, but we must tell the transport office about this.

## SECTION FOUR

## Side effect management

The following information is provided to help you to cope with any side-effects from chemotherapy. Everyone reacts differently to chemotherapy. No one has every possible side effect related to their chemotherapy treatment. The occurrence

## **Reproduction and sexuality**

Chemotherapy can interfere with both the female and male reproductive systems by affecting the ovaries and sperm. Some chemotherapy can cause temporary or permanent infertility.

#### Women

Menstrual cycles (periods) may become irregular or stop altogether and may not restart. Some women may find that their periods are heavier, irregular, and more frequent. The hormonal effects of chemotherapy may cause menopause-like symptoms such as hot flushes, mood swings, itching, burning or dry vaginal tissues. Tissue changes can make intercourse uncomfortable but can often be relieved by using water-based vaginal lubricants. You may also find you are more prone to vaginal infections. Avoid oil-based lubricants (petroleum jelly); wear cotton pants and tights with a cotton ventilated lining. Avoid perfumed soaps, lotions, and deodorants. Do not douche unless recommended first by your doctor.

Tell your doctor if you have signs of a vaginal infection immediately (vaginal burning, itching, strong odour or discharge, burning when passing water).

If you are of child-bearing age, you may still be able to become pregnant while taking chemotherapy. But this is NOT advisable because most chemotherapy can cause birth defects.

You must use effective birth control throughout your entire treatment and for a minimum of one year afterwards. If you have questions and concerns about this, please speak to your doctor before your treatment.

## Skin care

Some chemotherapy may cause minor skin changes. Side effects include dryness, redness, itching, peeling skin, and/or acne, nail brittleness, ridging, and darkening.

- use creams/lotions daily. Apply after bathing while your skin is still moist (E-45, Aveeno, sunflower cream, lanolin-based lotions)
- avoid lotions, perfumes and aftershaves that contain alcohol
- inspect your skin daily for cracking or peeling. Notify the clinic if you have breaks in the skin
- ridging and darkening of the nails often cannot be avoided but will disappear once the chemotherapy is finished
- try to avoid acrylic/gel or false nails because they break down the skin and cuticles. Nail polish is fine.

Many chemotherapy medications increase your sensitivity to the sun, causing severe sunburn, even for some time after chemotherapy or radiotherapy has finished.

Therefore it is highly recommended that you use a sunscreen daily of SPF 15 or higher even in dull conditions when working or spending time outside.

- waterproof and sweat-proof products work best
- apply first thing in the morning, frequently throughout the day if you are outside, and wear a hat and protective clothing
- keep a small tube in your handbag, car, etc to have available to reapply if needed.

and severity of side effects vary greatly from person to person. Some people experience no side effects and are able to carry on a normal life. The nurse and doctor will discuss the specific side effects of the chosen treatment you may experience

#### What causes side effects?

Cytotoxic Chemotherapy drugs are designed to kill fastgrowing cancer cells. These cells grow and divide rapidly. However, some healthy cells also multiply quickly, and chemotherapy affects these cells as well. The fast growing, healthy cells most likely to be affected are:

- blood cells forming in the bone marrow
- cells within the digestive tract (stomach, bowel)
- hair/skin follicles
- cells in the reproductive system (uterus, ovaries, testicles)

Immunotherapy works by enhancing one of your body's natural defences against cancer, called the immune system. These drugs often have different side effects.

## How long will the side effects last?

Most normal cells recover quickly after chemotherapy. Many side effects disappear as healthy cells have a chance to grow normally.

The length of recovery time is different for everyone and for each side effect.

Many side effects go away quickly, some may go between treatments, but others may take months to disappear completely.

Some may cause possible permanent damage to the reproductive organs and occasionally the heart, lungs and kidneys.

Your doctor and nurse will discuss with you the risks and long term effects both before and during your treatment. It is important to remember that many people have no long-term effects.

It is also reassuring to know that great progress is being made in preventing and managing some of chemotherapy's more serious side effects.

The side effects of chemotherapy may often be unpleasant, but they must be balanced against the treatment's ability to destroy cancer. You will not be asked to continue any treatments unless the benefits greatly outweigh the effects. Most side effects can be treated, so it is important that you tell us of any you are experiencing.

At all times your views and opinions will be included when the decision is made as to the best treatment for you. You can also decide to stop treatment at any time if you wish.

The following pages list the most likely side effects and suggest ways they can be managed. Please remember to consult your medical team with any questions and/or concerns.

#### **Blood cells**

Your blood cells, which are made in the bone marrow, will be affected by the chemotherapy. Before each treatment you will have a blood test. This will tell us the number of blood cells you have in your body. The blood cells that we look at are:

- build up exercise gradually and listen to your own body telling you when it has had enough
- don't have high expectations of yourself at this time.
   Do what you can, one day at a time
- consider a relaxation/meditation class or yoga class to help you to learn to relax your mind and provide gentle exercise. (Make sure you notify any instructors about your condition prior to beginning a new class)
- keep a normal sleeping routine, and sleep just long enough to feel refreshed
- a regular wake up time may help you throughout your treatment and allow your body to adjust
- avoid stimulants such as coffee, alcohol, and chocolate prior to going to sleep
- try reading or listening to soothing music to help to relax your mind and lessen the tension in your body
- take a warm bath before going to bed and establish a routine for going to bed each night.

The wellbeing programme is available for patients during and after cancer treatment. It features education, information and tailored physical activity designed to meet individual needs contact 01722 425085.

- to keep as much mobility as possible, ask your doctor for a physiotherapy assessment
- get up slowly, move purposefully and wear nonslip shoes.

## **Metastatic Spinal Cord Compression**

For some people the cancer can affect their bones. If cancer is in the spine there can be a risk of pressure on the spinal cord by either the cancer or the effect of cancer on the bones. If you have any of the following symptoms, you may need prompt treatment in hospital:

- back pain or change in existing back pain in association with one or more of the following symptoms:
- weakness, heaviness or stiffness in your limbs
- numbness or tingling/pins and needles
- alteration in bowel and/or bladder function
- back pain at night.

A delay in seeking help could make it more difficult to provide effective treatment.

#### Exercise and rest

Due to activity level changes and fatigue, you may find that your ability to exercise and sleep changes. The following suggestions may be helpful in adjusting to these changes:

 regular light exercise can reduce tiredness and improve sleep. It can also help your energy levels return more quickly after treatment.

#### Red blood cells

These cells contain haemoglobin which carries oxygen to your body. If these red cells are low you may feel:

- very tired
- dizzy
- short of breath with effort
- you may look 'pale'.

If they become too low your treatment may be delayed, or you may require a red blood cell transfusion.

Things you can do to help:

Tell us if you are: very tired, dizzy, short of breath with effort, or look 'pale'. You should:

- get plenty of rest
- drink plenty of fluids
- eat a well balanced diet
- limit your activities
- ask others for additional help as needed
- when sitting or lying down get up slowly to help prevent dizziness.

#### Platelet cells

These cells help your blood to clot and prevent excessive bleeding. If you notice:

- any bleeding from your nose or gums
- any excessive bruising
- unexpected pinkish urine
- black or bloody stools.

call your medical team immediately. You may require a platelet transfusion.

If your platelets are low but you are not in need of a transfusion:

- it is important to consult your doctor before taking any over-the-counter or new medicines, including aspirin and/or ibuprofen-based products
- be careful when using sharp objects and avoid any type of contact sports or activities
- use a very soft toothbrush to clean your teeth
- blow your nose very gently
- do not have any type of injections unless you consult your haematology/oncology team first
- avoid lifting anything heavy
- avoid getting constipated and having to strain.

## Aches and pains

Some chemotherapy medications may have specific effects on your nervous system, producing aches and pains, numbness or tingling, and/or muscle weakness.

You will be told about this if it is likely to happen. However, notify your clinic immediately if you experience any of the following:

- loss of balance
- difficulty walking (feeling like you are 'walking on pebbles')
- difficulty picking up objects or buttoning clothing
- sudden jaw pain
- hearing loss, or ringing in your ears
- severe stomach pain and constipation.

Often, mild muscle aches and numbness or tingling are expected and will be watched closely. Sometimes these are temporary and will go away after the chemotherapy is finished.

Some may take longer to go away or may not completely disappear at all. A few things you can do to help if this happens are:

- wear gloves when working in the kitchen or in the garden
- be careful when grasping hot, sharp, or slippery objects
- use handrails, canes and walking assisted devices when necessary for safety

- add full cream or dried milk to soups, stews and casseroles
- enjoy your desserts or puddings when you can!
- add high calorie supplements like Build Up or Fortisip.

## Weight gain

Occasionally some people experience weight gain while having chemotherapy.

This is not unusual and can be due to many things.

You may feel that you are too tired to follow your normal activity or exercise regimen; your metabolism may slow down as your activity slows down.

Some people increase their food intake as a comfort measure or find that they are eating more frequently simply because they are at home and don't have the energy to do anything else.

For some people it helps to relieve their nausea by eating frequent small snacks that may be high in calories.

If you need to take high dose steroids as part of your treatment then this can increase your appetite and cause weight gain.

This is not the time to diet. However, eating a well balanced, sensible diet is advised. Most people find that after their chemotherapy is finished and their energy levels return, they will lose naturally any weight gained.

## White blood cells

White blood cells protect your body from infection both from the normal bacteria in your body and the bacteria everyone is exposed to daily.

Many of these white blood cells will be destroyed by the cytotoxic chemotherapy. Your white blood cell count can be very low approximately 10-14 days after each dose of chemotherapy. At this time you will be at greater risk of getting an infection.

During your chemotherapy treatments your blood will be checked regularly.

If your white blood cell count is too low you may not receive your chemotherapy that day.

## Infection and what to look out for

An infection can begin in almost any part of your body, for example in your:

- mouth
- skin
- lungs
- urinary tract
- gastrointestinal tract
- reproductive system
- blood.

Signs of an infection can include:

- fever (high temperature) greater than 38°C (100.4°F)
- chills or shivering
- flu-like symptoms
- severe cough or sore throat, chest pain
- loose bowels
- burning feeling when passing water
- unusual discharge, redness, swelling or tenderness around a wound, sore, or catheter site.

Most infections come from the bacteria normally found on the skin and in the intestines and/or genital tract. In some cases the cause of an infection may not be known.

If you do develop an infection it needs to be treated urgently, to prevent serious complications.

## H.E.A.T - history - examination - action - treatment

When you start chemotherapy you will be given a H.E.A.T. rapid response card. The reason for this is it can be very dangerous if you develop symptoms suggestive of an infection whilst on chemotherapy. This can be life threatening. We want to ensure that if you attend Accident and Emergency or The Medical Assessment Unit, especially in another hospital, that you get prompt treatment. Always show this card to the nurse or doctor who sees you. Of course we prefer that you phone us first and attend this hospital, where we know your treatment and the care you need.

You will need an urgent blood test to check your white cell count. You may require antibiotics until your white count improves.

## Taste changes

Chemotherapy can alter the taste of foods you normally enjoy or make food taste bland. Some foods may taste like 'metal' due to the chemotherapy you are receiving. Several suggestions you can use to help are:

- rinse your mouth out with lemon, pineapple, or citrus juices
- use PLASTIC utensils when eating and glass or plastic containers to cook in whenever possible
- if red meats taste bitter (it's the iron!), try chicken, pork, turkey, fish, eggs, or beans as protein sources
- coffee, tea, and wine often increase the metallic taste so avoid them with meals
- try 'metallic' foods again later; what tastes 'off' this week may work next week.

## Weight loss

Without good nutrition and protein your body cannot heal properly and you may experience tiredness and weight loss as a result. Ways you can improve your calorie and protein intake are:

- add full fat milk, cream, honey or syrup to foods to sweeten and increase calories
- eat 4-6 small frequent meals a day instead of three large ones
- increase your intake of eggs, fish, fruits, vegetables, oils and peanut butters for protein

- plan your activities during the time of day you seem to have the most energy. Prioritise tasks and listen to what your body is telling you!
- organise shopping, chores, etc to use as little energy as possible. Allow family, friends, and neighbours to help
- get plenty of rest at night and take naps during the day if you can. If you are having trouble sleeping, tell your doctor
- eat small, frequent, well-balanced meals. Food acts as fuel for your body and is essential.

Fatigue can last for a few months after chemotherapy but gradually your energy should return.

#### **Nutrition**

Chemotherapy can cause lots of changes to your eating habits and how much you eat.

Many people experience taste changes, loss of appetite, and weight loss.

It is important to check your weight if you are having difficulty eating. You may not feel like eating normally. You will need to find the foods that suit you at this time.

Please notify us if you are having difficulty so that we can offer you dietary advice. We are able to make many suggestions as well as ask a dietician to see you. The dietician will help to develop an individual food plan for you.

There is lots of information available for you to take away in our waiting area in clinic and on the Pembroke Suite.

## If you notice any signs of infection you must contact the hospital or clinic immediately!

We advise you to:

- avoid people with known infections during your "low white count" period
- maintain healthy eating habits and sleeping patterns
- have a thermometer handy to check your temperature if you are feeling unwell.

## Nausea and vomiting

Nausea and vomiting can be a common side effect with some chemotherapy. However, we have very effective anti-sickness drugs that can help prevent this.

You will receive anti-sickness tablets before each chemotherapy treatment.

You will also be given additional tablets to take at home. Please take them as directed, usually half an hour before food and on a regular basis for several days after your chemotherapy.

You may also be given small doses of steroid tablets which help to control nausea and vomiting. They should be taken with food.

If the anti-sickness tablets are not effective (you are unable to eat or are vomiting), please contact the clinic immediately.

There are many different medicines we can give you to help with nausea. Do not wait until you feel sick to start taking your medicines – prevention is the key to not feeling sick! It is important that you:

- continue to drink plenty of fluids ( 4 pints or 2 litres of fluid every day)
- eat small frequent meals consisting of low fat, non-spicy or greasy foods
- avoid strong-smelling foods and scent
- ginger, barley sugar water, and/or boiled sweets may also be helpful throughout the day.

## Skin reactions

Occasionally you may experience a skin reaction to chemotherapy. Some chemotherapy can cause rashes as well as discolouring along the veins. Please tell us if this happens.

## Specific effects of targeted cancer therapies

Scientists had expected that targeted cancer therapies would be less toxic than traditional chemotherapy drugs because cancer cells are more dependant on the targets than are normal cells. However, targeted cancer therapies have substantial side effects.

The most common side effects seen with targeted therapies are diarrhoea, liver problems such as hepatitis and elevated liver enzymes. Other side effects include:

- skin problems (acne-form rash, dry skin, nail changes, hair depigmentation)
- problems with blood clotting and wound healing
- high blood pressure
- gastrointestinal perforation (a rare side effect of some targeted therapies).

## General advice on side effect management

## Fatigue (tiredness)

See also section on exercise and rest.

Fatigue is recognised as the most common side effect reported by people receiving treatments such as surgery, radiotherapy and chemotherapy.

It can be very distressing and disabling. There can be many causes of fatigue:

- poor nutritional intake
- chemotherapy and its effects on your body
- loss of appetite
- pain
- breathlessness
- anaemia (low red blood cells)
- depression.

It is generally normal to feel very tired for one or two days after your chemotherapy has been given, but this usually goes away.

Fatigue can make climbing stairs, carrying out small chores, and performing daily activities very difficult to do.

Please tell your doctor if you are experiencing fatigue lasting more than a few days.

There are several ways you may try to cope with your tiredness:

• tell your doctor if you are taking any pain medications. Many can cause severe constipation.

#### Hair loss

Some chemotherapy drugs can cause hair loss or thinning. This can affect all body hair, not just the hair on your head.

The hair will grow back after chemotherapy has stopped and sometimes even before your treatment has finished.

This will be discussed with you before your treatment if it is a possible side effect.

If you do lose your hair, it will gradually thin; it will not disappear overnight.

We can provide help and advice with wigs as well as other types of head-wear, which may help you to cope with hair loss. There is a charge for wigs. If this causes concern please discuss with your nurse.

Please ask us to make an appointment for you to see our wig specialist if you are interested.

With some chemotherapy regimens we are able to offer scalp cooling which involves you wearing a cold cap when you have the chemotherapy to help prevent hair loss.

We cannot guarantee this method will save your hair and it does have its own side effects, which will be fully explained to you.

We can also offer advice on hair care during chemotherapy treatment.

Please ask your nurse for more information.

Beathing difficulties (cough, shortness of breath, chest pain)

## Extravasation

Some drugs have to be injected very carefully into your veins otherwise they may cause damage to your skin (extravasation injury). This is why the nurse takes such care with the injections. You may experience some discomfort and hardening of the vein which has been used, but if you develop pain and redness during the injection tell the nurse **IMMEDIATELY**. If your hand or arm is sore during or after chemotherapy please let us know so that an assessment can be carried out.

If you need to go to the toilet make sure your cannula is secure before you go and when you return to your chair or bed ask the nurse to check the cannula.

## Sore mouth

Some chemotherapy medications can cause mouth ulcers and/or sore gums and mouth. This can be very uncomfortable and prevent you from eating and drinking. Please contact us if you are having pain with eating, swallowing or have visible mouth blisters or white patches.

We can provide you with special mouthwashes to ease the pain and heal the sores. You may also have an infected blister which will need special treatment. There are several things you can do to help maintain good oral mouth care:

- regular cleaning of your teeth/dentures with a soft toothbrush
- rinsing 3-4 times a day after meals with warm salt water rinses (1 teaspoon of salt to 1 pint of water)
- avoid mouthwashes with alcohol in them (this dries the gums).

If you have a toothache please contact the hospital first as it may indicate an infection.

Before you start chemotherapy it may be worth having a dental check up. Always let your dentist know you are on chemotherapy.

## **Bowel changes**

#### Diarrhoea

Some chemotherapy medications may cause loose stools or diarrhoea due to the chemotherapy's effect on the cell lining of the intestines. If you have more than 2 diarrhoea episodes a day for more than 24 hours, or pain and cramping along with the diarrhoea, please call the clinic.

Do not take over-the-counter medicines for this without asking us or your doctor first. It can also be helpful to try the following things to help control the loose stools:

 eat small, frequent, low fibre foods (white rice or bread, creamed cereals, bananas, canned or cooked fruit, yoghurt, baked potatoes, boiled/baked chicken or turkey without the skin)

- avoid high fibre, greasy, spicy and/or high fat foods
- avoid coffee, tea, alcohol, milk products if they increase your diarrhoea
- drink clear liquids (juices, water, weak tea, broth, ginger) slowly at room temperature
- increase foods and liquids that are high in potassium (bananas, potatoes, peach and apricot juices)

## Constipation

Some people may experience constipation (or irregular hard stools) during chemotherapy. It is important that you contact the clinic if you have not had a bowel movement in 2 days or you are having difficulty and are passing hard stools.

You may need a laxative or stool softener. Do not take overthe-counter remedies without first contacting the clinic. Many laxatives take essential nutrients and fluids from your body and are not recommended.

You can also try the following ideas to help deal with constipation:

- drink plenty of fluids, especially warm ones
- increase your fibre intake by replacing white bread and cereals with wholemeal varieties.
- increase raw or dried fruits and vegetables with skins, seeds or pips and beans or pulses
- increase your exercise as much as possible. Simply getting out for a short walk can help
- do not ignore signs of urgency to have a bowel movement