Chemotherapy Patient Held Record

Beacon Day Unit  01823 342296
Beacon Oncology Ward  01823 344202
Haematology Ward 9  01823 342009
Personal Details

Insert patient label

Diagnosis

Consultant

G.P

Your Macmillan Chemotherapy Clinical Nurse Specialist is Vanessa Fountain
Tel 01823 344225

This diary is for you to keep as your own record of any treatment that you receive. The information provided includes:

- Important contact numbers
- Essential advice
- Details of your treatment regime
- Record of any blood results
- Pages for you to make your own notes
- Additional information that you may require can be added. Please discuss this with your nurse
The staff involved in your care will update this record at each visit so please bring it with you when attending the outpatient department, the day unit for treatment or any other hospital admission, including non-cancer specialities.

You may also find it useful to take it with you when visiting your G.P surgery or specialist nurse.

The information in this folder has been designed to help you understand your disease and its treatment so that you can participate to a greater extent in your care.

All questions no matter how simple are important to you and therefore, do not hesitate to ask your doctor or nurse for their advice.

This record is not intended as a substitute for talking to those people caring for you.
Essential Information

You must contact the day unit immediately if you develop any of the following symptoms of infection:

- A temperature of 38°C (100°F) or higher at any time or above 37.5°C (99.5°F) at any 2 readings taken an hour or more apart
- Or any of the following symptoms with or without a temperature:
  - Shivering or sweating episodes
  - Feeling generally unwell or experiencing flu-like symptoms
  - Chesty cough
  - If you have a PICC line or central line and have any redness or discharge around the site or if you experience any episodes of shivering when the line is flushed

Do not delay, as treatment may be required urgently.

The Beacon Centre Day Unit is open Monday to Friday 8.30am – 5.00pm
Telephone 01823 342296

In the evening, at weekends or bank holidays you should contact one of the following numbers:

If you are being treated by the Oncology team, call the Beacon Ward – Telephone 01823 344202

If you are being treated by the Haematology team, call Ward 9 – Telephone 01823 342009

Attempting to contact a GP out of hours may result in a delay in treatment.
You should also contact us if you develop any of the following symptoms:

- Bleeding from the gums or a nosebleed that does not stop after applying pressure for 10 minutes
- Bleeding from the back passage or blood in the urine
- Unexplained bruising or clusters of red-purple spots on your body
- Vomiting that continues despite taking anti-sickness tablets
- Diarrhoea – four or more bowel movements more than normal or diarrhoea at night
- Mouth ulcers that stop you eating or drinking
- Worsening shortness of breath – however, If you experience a sudden onset of shortness of breath and/or chest pain you should call 999 immediately
- Any pain, redness, swelling or blistering around the site of your chemotherapy injection
Chemotherapy

What does it mean?
Chemotherapy simply means drug treatment that is given to destroy or control cancer cells. There are many different drugs that attack cancer cells and each works in its own unique way. They can be given on their own or in a variety of combinations with other drugs in order to increase their effectiveness.
Biological therapies are also being increasingly used, either alone or as part of a chemotherapy regime, to destroy cancer cells. There are several different types of treatment including monoclonal antibodies and cancer growth inhibitors. If any of these treatments are suitable for you your consultant will discuss them with you.

Why is it given?
The aim of chemotherapy treatment will depend on what type of cancer you have and what stage it is at. It can be given;

- To cure the cancer
- To shrink a tumour prior to surgery
- After surgery or radiotherapy to destroy any remaining cancer cells and reduce the risk of the cancer returning
- To relieve symptoms by reducing the size of the tumour

How does it work?
Whether you have chemotherapy by mouth or injection, the drugs are absorbed into the blood
system and the blood carries the drug to the cancer cells. These drugs interfere with the ability of the cell to divide and reproduce. Each drug that you are given will act in a slightly different way. Because the normal cells in your body also divide, they can be affected by chemotherapy. These side effects are usually temporary and permanent damage is rare with most chemotherapy treatment. For more detailed information on your individual treatment, please refer to the Cancer Backup information sheet that you have been given.

How is chemotherapy given?
- By mouth as a tablet, capsule or liquid
- Directly into a vein. This can be as a bolus (rapid) injection, slower infusion or by pump over a number of hours or days. This can be given through a cannula (small plastic tube) in the back of the hand or arm, which is removed when each cycle of treatment is completed. Some patients may require a catheter line passed into a vein in the chest (central venous catheter) or upper arm (PICC line). These devices are left in place for the duration of treatment.
- Injection into the spine – this route is not commonly used, but if required for your treatment regime it will be explained fully.

Where is treatment given?
Depending on what treatment you are receiving
- In the Beacon Centre Day Unit on an outpatient basis
• On the Beacon Centre Oncology Ward as an inpatient
• On Haematology Ward 9 Musgrove Park
• Satellite clinic at Dene Barton or Bridgwater Hospital
• At another hospital, for example, the Bristol Haematology Oncology Centre or Yeovil District Hospital

What is Pre –Assessment?
Before each cycle of chemotherapy treatment you will be asked to attend the outpatient department for a pre-assessment appointment. This usually takes place 1-3 days prior to treatment. You will have blood tests taken and see a doctor, pharmacist or chemotherapy nurse specialist. This is to ensure it is safe to proceed with your treatment as planned and that you have an opportunity to discuss any side effects you may have.

Extravasation
Although the placement of a needle into your vein can cause discomfort the treatment itself should not cause pain. Extravasation means that chemotherapy has leaked out of the vein into the surrounding tissues. It is important that if you feel pain, discomfort, burning, stinging or notice any redness or swelling around the needle site, either during or after treatment, you should inform your nurse immediately. This also applies if you have a PICC or Central Line.
Common Side Effects

Everyone reacts differently to chemotherapy treatment. We can offer you help for most side effects so please tell your doctor or nurse how you are feeling.
This section outlines some of the common side effects. For further information on possible side effects specific to your treatment, please refer to your Macmillan Cancer Backup sheet.

- **Bone Marrow Changes** – The bone marrow is the ‘factory’ where your blood cells are made. These consist of red and white cells and platelets. For more information on how chemotherapy affects your bone marrow please read the section ‘Understanding Blood Results’.

- **Nausea** – It is common to feel sick (nausea) during and after each cycle of treatment, although this is not a side effect of every drug. Anti-sickness medications will usually help and are commonly given at the time of treatment and, if needed, a supply can be given to you to take home. There are different types of anti-sickness drugs so if one does not work for you then please tell your doctor or nurse so that we may change your medication.

- **Mouth Care** – during chemotherapy you may develop a sore mouth. To help to minimise this, it is important to clean your teeth or dentures
after each meal and before going to bed each night. Cleaning your teeth with a soft toothbrush may be more comfortable. Drink as much water based fluid as possible aiming for 2-3 litres (approximately 4-6 pints) per day. If your mouth does become sore it is important to discuss this with your doctor or nurse when you attend for pre-assessment or treatment or if you are unable to eat, telephone for advice.

- **Diarrhoea and Constipation** – Both of these side effects can be easily managed, however, if you have four bowel movements more than normal or diarrhoea at night please contact us – see ‘Essential Advice’ section. Many painkillers and some anti-sickness medication can cause constipation; it is advisable to take regular laxatives with them.

- **Appetite** – During your treatment you may find that your appetite reduces and you are eating less, which may lead to weight loss. It is important to try and keep your weight as stable as possible and that you keep well nourished. There is additional nutritional information available if you should require it and if necessary you may be referred to a dietician. Should you have any further questions or concerns then talk to your nurse or doctor.

- **Taste Changes** – Chemotherapy can sometimes affect your taste. This can involve loss of taste, bitter or metallic taste or foods tasting sweeter or saltier than usual. Normal
taste should return around 2-3 months after treatment has finished. If you are having problems please discuss them with your nurse.

- **Fatigue** – Fatigue is a feeling of extreme tiredness or exhaustion. It is a common problem for patients and may be due to the cancer itself or the effects of the treatment. It is important that you explain exactly how you feel to the doctor or nurse, as they may be able to help you minimise these problems.

- **Rashes** – rashes do occasionally occur as a result of your chemotherapy and should always be reported to your doctor or nurse.

- **Allergic Reaction** – a small number of patients may experience a reaction to certain chemotherapy drugs. Should you experience any difficulty in breathing, a cough, a swelling in the throat or mouth, facial flushing or other unusual symptoms during treatment please inform a nurse immediately so that you may be treated appropriately.

- **Hair Loss** – Some types of chemotherapy can cause temporary hair loss (alopecia). This can be partial or complete and may involve all body hair. However the hair will re-grow when chemotherapy treatment has finished. There is a weekly wig clinic held at the Beacon Centre. Your nurse will supply more information on hair loss and the wig service if this is appropriate to your treatment.
General Advice

Dental Care
You should inform your dentist that you are receiving chemotherapy treatment. If you require dental treatment please discuss this with one of the chemotherapy nurses or doctors first.

Vaccinations
The flu vaccine is usually recommended for people having chemotherapy but it may be less effective under these circumstances. Please check with your chemotherapy nurse or doctor as to when it would be the best time to receive it.
You should not receive any ‘live virus’ vaccinations, e.g. certain polio vaccines, measles, rubella, BCG or yellow fever.

Fertility & Sex Life
You can continue to have a normal sex life during chemotherapy although you may find that your interest has decreased.
Women sometimes find that their periods become irregular.
For men, the sperm count may be reduced but it will usually return to normal once treatment stops. Some drugs however may cause permanent sterility. If this is likely to occur you will be advised and sperm banking may be offered.
In all cases barrier contraception should be used as you should not become pregnant or father a child whilst receiving chemotherapy.
If you remain sexually active during the time you are on treatment, it is advisable to use the extra precaution of condoms to reduce any risk of any problems for partners or infection for you. You may also be asked to confirm you are not pregnant or planning a pregnancy before you start treatment.

**Alcohol**
Generally it will be quite safe for you to have a small amount of alcohol but there are a few drugs that will interact. You will be advised if alcohol should be avoided.

**Skin Care**
It is inadvisable to sunbathe whilst on treatment as your skin and eyes may become more sensitive to the effects of sunlight. However, sitting in the shade will not be harmful. Nevertheless, it is still advisable to always use a high factor sun cream whenever you may be outdoors for prolonged periods.

**Social Occasions and holidays**
There is no reason why you should not go out as long as you do not over tire yourself. If you are thinking of going on holiday tell your consultant. It is usually possible to arrange your treatment around your holiday but it does need careful planning. The Cancer Information Centre can provide more advice on Travel including getting insurance.
Avoiding Infection

In order to minimise the risk of acquiring an infection during your treatment you may want to take the following precautions.

- Hand washing – ensure you clean your hands regularly and ask any healthcare workers if they have cleaned their hands before examining or treating you. Alcohol rub should be readily available in all areas of the Beacon Centre.
- Ensure you maintain good personal hygiene and brush your teeth regularly with a soft bristle toothbrush.
- When gardening wear gloves to protect your hands.
- Stay away from people with a known infection, such as flu, chickenpox or diarrhoea and vomiting.
- Avoid any contact with animal waste and wash your hands after handling pets.
- Avoid eating ‘high risk’ foods including; raw or undercooked eggs, soft ripened cheeses, blue veined cheeses, live yoghurts and probiotic drinks, all unpasteurised dairy products, pâté, shellfish and takeaway meals. Wash salads and fruit well. Ensure food is cooked thoroughly. Do not reheat food.
Understanding Blood Results

While you are having chemotherapy blood tests will be taken before each cycle of treatment. This is because chemotherapy can affect the bone marrow, which makes blood cells. It is important to ensure that your blood count has returned to a safe level before continuing with treatment. The level at which it is safe to give treatment will depend on which drugs you are receiving and sometimes blood counts will always remain below “normal” on chemotherapy but within a safe range for you.

If your blood count is not within the satisfactory range your treatment may have to be delayed or the dose of chemotherapy drug reduced. This will be explained to you by your doctor or nurse.

The main effects of chemotherapy on the blood are:

- **Infection** – white blood cells (WBC) help to fight infection. Neutrophils are one type of white blood cell, which will be monitored. If your white blood cell and neutrophil count are low then you may be more prone to infections.

- **Bruising or Bleeding** – Platelets are the cells, which help your blood to clot. If your platelet count is lowered, you may notice that you bruise or bleed more easily. If you notice any side effects such as bleeding gums, nose bleeds or small groups of red-purple spots on your skin then you should inform your doctor or nurse.
- **Anaemia** – Red blood cells contain a protein called haemoglobin (Hb) which carries oxygen around the body. If your haemoglobin is low, you may become anaemic. Symptoms of anaemia are tiredness, breathlessness and dizziness. Eating a diet rich in Iron may help but sometimes it is necessary to have a blood transfusion.

Some types of chemotherapy drugs may have an effect on the liver or kidneys therefore additional blood tests may be taken to monitor these.

A special type of blood test called a tumour marker may be used to monitor some types of cancer. Your consultant or specialist nurse will explain if this is applicable to you and what the results mean.
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Chemotherapy Regime

Your chemotherapy treatment is called:

__________________________________________________________

It consists of the following drugs

________________________________ on day _________

________________________________ on day _________

________________________________ on day _________

________________________________ on day _________

________________________________ on day _________

________________________________ on day _________

Frequency of treatment:

__________________________________________________________

Number of treatments: _____________
**List of Medications**

Your nurse will complete this list of additional drugs that you will be given to take home. You can also keep a record yourself of what you take and when. Certain drugs (e.g. aspirin and warfarin) can interact with Chemotherapy.

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Patient’s Notes

This section is for you to record any notes that you would find useful. For example, you may wish to keep a record of any side effects that you are experiencing or a list of questions that you would like to ask at your next hospital visit.

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Healthcare Services

During your treatment you may come into contact with a number of different Healthcare professionals who will provide different services that may benefit you. Some of these you may already be familiar with. Your hospital team will correspond regularly with your GP to ensure that they are aware of your progress. If you should require any additional services your GP or hospital team can refer you.

These healthcare professionals may include:

- Community nursing team – based at your GP’s surgery. Can provide some nursing care at home including practical advice, care of PICC or central lines, blood samples and wound care.

- Community Palliative Care Nurses or Macmillan Nurses – are specialist nurses who are highly skilled in pain and symptom control and can offer practical advice and emotional support at home.

- Dietician, Occupational Therapist or Physiotherapist.
Additional Support & Information

Your diagnosis may provoke a variety of reactions. When first told you may feel a mixture of emotions such as shock, fear, anger disbelief or you may feel nothing at all. Suddenly life seems very different. All these feelings have been well described by people in this situation. It can also have a profound effect on those close to you who may be feeling similar emotions.

With time, these feelings may subside but coming to terms with the situation and learning how to cope can also be very stressful and will always be individual.

Having information and feeling supported has been shown to reduce uncertainty, anxiety and depression. Do not be afraid to ask questions or to ask for information. Knowing more about your disease and its treatment can reduce tension and enable you to retain some control over your life.

Remember, advances are being made all the time. What you or your family and friends think you know may not be correct or up to date.

Always check whether you have understood what you have been told and ask for explanations if necessary. Being given information, feeling supported and having the opportunity to talk things through can all have a place in adjusting to your diagnosis.

Many leaflets and booklets about the different diseases and their treatments are available at the hospital.
Support

Patients having chemotherapy may also experience emotional and social problems such as:

- Difficulty sleeping
- Anxiety and depression
- Changes in personal / sexual relationships
- Financial worries

If you would like to speak to someone about any of these or other similar matters, please speak to your nurse.
Would you like more Information?

Do you have questions and forget to ask them during your appointment? Why not visit the Cancer Information and Support Centre, a free and accessible service for everyone.

We have a facility in the reception area of The Beacon Centre with the main centre located in the Old Building corridor towards the League of Friends shop.

Our telephone number is 01823 343839, Fax 01823 343840 or email cancer.info@tst.nhs.uk
The Centre is open from Monday to Friday 9.30am – 4.00pm (times may vary).

Just pop in anytime after your appointment, or between appointments. This service is designed to compliment the support, care and treatments you are receiving from other departments within the hospital.

The Centre, staffed by Information Nurse Specialist, Ann Treloggen, and a team of trained Somerset Cancer Care Volunteers, offer:

- Unbiased, confidential help and advice
- Up to date leaflets and contacts
- Continued support for as long as you need it
- Liaison with the Healthcare Professionals that care for you
- Assisted internet access
LOCAL & NATIONAL SUPPORT GROUPS

Cancer Information & Support Centre
Macmillan Information and Support Nurse – Ann Treloggen
Old Building, Musgrove Park Hospital, Taunton, Somerset TA1 5DA
Telephone: 01823 343839, Fax: 01823 343830,
email: Cancer.Info@tst.nhs.uk

Somerset Cancer Care (Local charity providing emotional support for people affected by cancer)
Somerset Cancer Care Lead – Sue Hasler
Telephone: 0800 7314608
Website: www.somersetcancercare.org.uk

Somerset Direct (A Somerset County Council information and advice service for older people, carers, relatives and other adults with care needs)
Telephone: 0845 345 9133
Website: www.somerset.gov.uk
Email: adults@somerset.gov.uk

We are Macmillan.Cancer Support also includes Cancerbackup
(Cancer Information specialist nurses give information on all aspects of cancer and its treatment)
telephone: 0808 800 1234
Websites: www.cancerbackup.org.uk
www.macmillan.org.uk
89 Albert Embankment, London, SE1 7UQ

Cancer research UK
0808 800 4040 Mon – Fri 9am-5pm
www.cancerhelp.org.uk
Cancer Aid For Everyone

CAFÉ – Informal drop-in centres, welcoming anyone affected by cancer, where patients and carers are able to offer each other support in a warm and friendly atmosphere. Highly trained volunteers are there to:

- Be a listening ear
- Provide information
- Help you to contact other services
- Help in any way they can

The venues are very comfortable, with separate areas for privacy if needed. Light refreshments and free complimentary therapies all help to make CAFÉ a very special place to be.

It does not matter where you live; you are welcome to talk to one of the volunteers on the phone, arrange a home visit or go to one of the local drop in centres.

Cancer Aid For Everyone drop in centres:

TAUNTON: Robin Close Hall, Robin Close, Bishops Hull
  Tuesdays 10am – 12noon
MINEHEAD: The Methodist Church Hall, The Avenue.
  Mondays 2pm – 4pm
WELLS: St Lawrence Day Centre, Chamberlain Street
  (off Union Street car park)
  Fridays 10am – 12noon
WESTON-SUPER-MARE:
  Summer Lane Care Home, Diamond Batch, Worle.
  Tuesdays 10am – 12noon
YEOVIL: Methodist Church Vicarage Lane (Lower Quedam)
  Wednesdays 10.30am – 12.30am

Call Freephone 0800 7314608 for further information.
Dear Patient, Relative, Friend or Carer

Re: Your Views on Our Service

Please feel free to comment on any issues concerning your care, the environment in which your treatment has been delivered and the service offered by the Beacon Centre.

Please complete the form below, which provides you with an opportunity to make your opinions known to us, in confidence, should you so wish.

Many thanks for your co-operation.

Andrea Mostyn-Jones
Matron, Cancer Services

Your views on our service

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Name........................................Date..................