





CONTENTS RELATED SIDE EFFECTS......18 Intravenous Drip18 THE NORTHERN SYDNEY Other Ways of Having CANCER CENTRE 4 Chemotherapy......19 Introduction......4 Infection19 Operating hours.....4 COVID-1919 How to contact The Northern Infection: general Information20 Sydney Cancer Centre5 Signs of infection......20 Car parking5 Preventing Infections22 Mobile phones......6 How do infections occur?.....22 Televisions and other electronic devices......6 Presenting for chemotherapy with a cough or cold.....23 Visitors 6 Bleeding......24 Meals 7 Anaemia......25 **RNSH Patient Information** Mouth Care......26 and Support Services.....8 Cansupport......8 Dental Care......27 Emotional care......9 Bisphosphonates and other Useful Contacts and Other bone targeting agents27 Support Services......10 Nausea and Vomiting28 RNSH Cancer Health Services 12 Anti-nausea medication 28 Cancer helpline12 Bowel Care30 Nurse Practitioner Symptom Clinic....13 Diarrhoea......30 Palliative care services14 Constipation......30 Pancreatic Cancer Centre14 Nutrition......31 Clinical trials unit.....14 Skin Care.....32 Apheresis Unit......15 Nail Care......33 Nerve Damage33

CHEMOTHERAPY AND

Fatigue	3/
_	
Hair Loss	
Fertility	
Excretion of Chemotherapy	37
IMMUNOTHERAPY AND RELATED	
SIDE EFFECTS	38
Immune Related Adverse Events	39
TARGETED THERAPY	40
Managing Side Effects from	
Targeted Therapy	41
RADIOTHERAPY AND RELATED	
SIDE EFFECTS	42
Skin Care	42
Do's and don'ts	43
Soothing the skin	44
Sunscreen	44
Swimming	44
Diarrhoea	44
Medications	45
Mouth Care	45
Dry mouth	46
Medications	46
How to manage a sore	
and painful mouth	47
Nausea and Vomiting	47
Hair Loss	48
Radioactivity	48
Total Body Irradiation (TBI)	49

SENERAL INFORMATION	
OR ALL PATIENTS	50
Exercise	50
Smoking and Cancer	5C
Sexuality	5
Fertility and Cancer	51
Medication Safety	5
Consent	52
Preventing a Fall in Hospital	53
Inpatients/outpatients checklist	
for carers and relatives	53
Tips to prevent a fall in Hospital	54
Useful Websites	54
Australian websites	55
Resources for adolescents	
and young adults	56
International websites	56
Visitor Map	57
ACKNOWLEDGEMENTS	58
Consumer review	58
Notes	59

THE NORTHERN SYDNEY CANCER CENTRE

"The Northern Sydney Cancer Centre would like to acknowledge the Traditional Custodians of the Northern Sydney region, the Gaimariagal, Guringai and Dharug peoples. Their spirit can be found across the region and we honour the memory of their ancestors and Elders, past and present.

As we endeavour to serve the health needs within the community, we recognise the importance of the land and the waterways, as an integral part of people's health and wellbeing".

Introduction

The purpose of this patient booklet is to provide up to date, relevant information related to cancer treatments. Included in this booklet are useful internet websites and other support service information.

The Northern Sydney Cancer Centre (NSCC) is located within the Acute Services Building at Royal North Shore Hospital (RNSH). This new integrated public hospital facility opened in October 2012, and provides services including Radiation Oncology, Medical Oncology, Haematology, Apheresis, Venesection, Bone Marrow Biopsy Clinic, and Clinical Trials. The inpatient Oncology (8F) and Haematology (8E) wards are located on level 8 of the Acute Services Building

Access to the NSCC is via the main entrance on level 3 or via the back entrance of the hospital from Herbert Street. Take the orange lifts down to level one and present to the main reception area of the NSCC. The Centre can also be accessed from Herbert Street on level one.

Operating hours

The Cancer Centre is open seven days per week T: 9463 1199

The main centre operating hours are:

8am - 6pm Monday to Friday, and

8am - 4.30pm on weekends (Chemotherapy Day Unit only)

The Radiotherapy Unit is open Monday to Friday 7.30 - 5pm T: 9463 1300

How to contact The Northern Sydney Cancer Centre

T: 9463 1199 (weekdays 8am - 4.30pm)

On Saturday and Sunday, the Chemotherapy Day Unit nurses can be contacted on T: 9463 1230 (8am - 4.30pm)

For medical follow-up appointments T: 9463 1380

Chemotherapy appointments T: 9463 1230

Clinical trials Oncology T: 9463 1199

Clinical Trials Haematology T: 9926 4377

After hours contact:

For any advice regarding chemotherapy pumps, Port-acaths, Hickman or PICC lines, you may contact the inpatient wards 8F or 8F.

Ward 8E (Haematology)

T: 9463 2850

Ward 8F (Oncology)

T: 9463 2860



Car parking

Parking is available at a reduced rate for patients undergoing treatment or appointments at the NSCC. To be eligible for concession you will need to sign a concession parking form (NSCC staff will provide when you check in) and present your Wilsons parking ticket for validation to the administration staff at the front desk of the cancer centre each visit. On weekends present your yellow or blue appointment card and parking ticket to the RNSH Main Foyer Reception desk in the Acute Services building for validation. The first 3 hours are free and then after three hours there is a \$5.60 flat fee. Concession rates are only valid in the P1 and P2 multistorey car parks. They do not apply in parking meter bays. If you are a patient or carer for a patient attending the hospital more frequently than twice a week please speak to a member of staff about a concession for parking. This can be organised through the Department of Social work or by the Nursing Unit Manager of the ward. There is disabled parking available in all car parks at RNSH.

Mobile phones

Please minimise the use of mobile phones in the treatment area. Mobile phones should be switched to silent, and only used for urgent telephone calls. Prolonged, frequent use can be disruptive to other patients around you. Please speak to the nursing staff if you have any concerns. There is free Wi-Fi available in the Cancer Centre; please speak to a member of staff to access this.

Televisions and other electronic devices

Each chair space in the new NSCC Chemotherapy Day Unit has a flat screen television with free access for patients. You are welcome to bring in other devices such as laptops and iPads to use whilst you are having treatment (Note: the NSCC is unable to take responsibility for the safety of such items).

The inpatient wards are equipped with flat screen televisions. However, a hire fee is payable. To activate the television, telephone the company quoting your medical record number and make a payment. If you have private health insurance you have free television access and this is activated when you call the company and quote your medical record number. In addition, private health insurance provides a five-dollar weekly credit for outgoing telephone calls.

Visitors

You are welcome to bring one family member or friend with you to your treatment. However, visitors are not permitted into the Chemotherapy Day Unit, Oncology and Haematology wards if they have any symptoms of colds, flu, runny nose, coughing, shingles, diarrhoea, conjunctivitis or any type of respiratory infection. People will be asked to leave if found with the above symptoms.

Children under the age of 12 years are not permitted in the Haematology ward 8E and the Chemotherapy Day Unit.

Ward visiting hours

8F: Visiting Hours 10am – 8pm or by arrangement with the Nurse Unit Manager

8E: Visiting Hours 11am – 2pm and then from 3pm – 8pm or by arrangement with the Nurse Unit Manager. Note that 2pm – 3pm is the rest period.

There are some restrictions in the Haematology ward that include: **no children under 12 years, no flowers and no visitors that have signs of infection.**

If you are attending the Chemotherapy Day Unit for treatment please bring one support person only. The Chemotherapy Day Unit does not have the capacity for large amounts of visitors and poses an infection risk to patients. Family members can take turns to visit by waiting in the coffee shop or courtyard areas.

Meals

If you are attending the Chemotherapy Day Unit you will be provided with morning and afternoon tea, and a simple meal for lunch. Patients in hospital receive a varied menu which caters for specific dietary needs. Please inform your treatment team of any dietary requirements. The hospital has a wide variety of shops and food outlets located on level 3 of the Acute Services Building (main building).

RNSH Patient Information and Support Services

Cansupport

Cansupport is a cancer information and support service based at the NSCC for people with cancer, their families and carers. Cansupport is part of your treatment team. Cansupport manages and maintains a comprehensive cancer information and resource centre, which is situated directly to the left of the main reception desk on level 1 of the Acute Services Building in the NSCC. The Resource Centre contains a wide selection of high quality, reliable information relating to all cancers and support services as well as general information on lifestyle and carer support. The Cansupport Team can link you with other members of your treatment team including Social Work and Clinical Psychology as well as provide assistance to access financial assistance, legal services and accommodation. The Resource Centre is open to visitors during the Centre's opening hours. Staff and volunteers are available for assistance and support from Monday to Friday 9am – 4pm.

In addition, Cansupport runs a Wig Library for patients who are receiving cancer treatment within the Northern Sydney region. The service is for women and men who may experience hair loss/alopecia whilst undergoing treatment. The service is available by appointment. To make an appointment for a wig fitting please contact T: 9463 1188, see page 35 for more information on this service.

Cansupport has a dedicated team of trained volunteers who support patients, families and carers as well as providing invaluable support to the running of the NSCC. Our team involves a number of peer support volunteers who have experienced cancer either as a patient or carer themselves. Volunteers are available in the Centre and for ward visits to provide support and information.

A number of supportive programs are run at the Centre and RNSH including Look Good Feel Better; a relaxation and meditation program; group education programs, including new patient orientation; and support groups. Visit the Resource Centre for more information or speak with a member of your health care team.



Contact details for Cansupport: T: 02 9463 1188

Email: NSLHD-CANSupport@health.nsw.gov.au

Face to Face: Drop into the Resource Centre or speak to the Program Manager

Emotional care

A diagnosis of cancer can be extremely distressing for you and your loved ones. Research evidence shows it can be helpful to talk about concerns with a health professional. Talking to a health professional may assist with managing symptoms such as depression, anxiety, sleep problems, fatigue, worry, relationship and communication difficulties. It may also be helpful to read a copy of the Emotions and Cancer booklet produced by Cancer Council NSW. A copy of this booklet can be found in the Resource Centre on level 1 of the NSCC. For referrals for professional counselling and support speak to a member of your health care team.

Useful Contacts and Other Support Services

Location of specialist consulting rooms: There are two different locations where you may be asked to see your doctor. There are specialist consulting rooms in Suite 9, Level 4 of the North Shore Private Hospital located adjacent to RNSH in Westbourne Street. There are also specialist consulting rooms on level 1 of the NSCC, Acute Services Building, RNSH. For this location you need to take the orange lift and present to front desk of the NSCC.

During your treatment you and your family or carer may need advice and assistance from health care workers other than nurses and doctors. Contact the following for information and advice:

Aboriginal Health Services T: 131 120 Mon-Fri 8.00am-4.30pm

The Aboriginal Health Service (AHS) is based at Royal North Shore Hospital (RNSH) and works within the boundaries of the Northern Sydney Local Health District (NSLHD) to provide culturally sensitive and appropriate care to Aboriginal and Torres Strait Islander people.

Chemotherapy Day Unit Care T: 9463 1230 for appointments

Oncology/Haematology Outpatient Day Treatment Unit located on level 1, Acute Services Building.

Cancer Council Helpline T: 131 120

Support and information on cancer and cancer related issues.

Cansupport at RNSH T: 9463 1188

Provides information, supportive care and programs for people with cancer, their families and carers.

Located on Level 1 Cancer Resource Centre

Carer Support Service Northern Sydney Local Health District T: 8877 5349

Information, education, advice and guidance to carers in our hospitals and in the community.

Chaplain

Available 24 hours a day for spiritual and emotional needs.

Leukaemia foundation T: 1800 620 420

The Leukaemia Foundation provides support and education for haematology patients and families. Transport services available.

Myeloma Foundation Australia provides support and education for haematology patients and families.

T: 1800 693 566 website www.myeloma.org.au

Patient representative T: 9926 7612

The patient representative is a service provided by the hospital where you can discuss problems concerning your treatment in hospital.

The following services can be arranged by your health care team.

Clinical Psychologist

To help you and your carers/family cope with any anxiety or stress you may be experiencing.

Dietician

A referral to a dietician can be organised by your doctor or nurse to provide advice on nutrition.

Interpreter service

This is a free service available by appointment.

Palliative care

To assist with symptom control, both in hospital and at home.

Pharmacist

To provide you with advice, education and information about prescribed medications.

Social worker

To provide you with emotional support and counselling, advice on financial matters, support services including transport and accommodation.

Sydney Home Nursing Service

To provide you and your carer with practical and emotional support at home.

RNSH Cancer Health Services

Cancer helpline

At the Northern Sydney Cancer Centre (NSCC) we are continuously striving to develop and introduce innovative ways to support our patients. In February 2019 we launched a telephone helpline to provide access to a clinical nurse consultant to assist patients who have symptoms or need advice about their cancer treatment. This helpline complies with the Australian Commission for Safety and Quality in health care by enabling a point of access for patients and their families to communicate with a health care professional about cancer treatment related questions and problems.

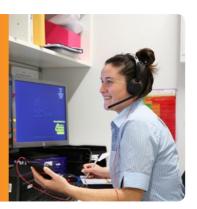
If you or a family member are currently undergoing cancer treatment and have concerns about side effects from treatment, you can speak with our cancer nurse consultant by calling the telephone number below. This is a free call.

Northern Sydney Cancer Centre - Cancer Helpline -



\$ 1800 965 222

8am - 4.30 pm, Monday to Friday (not available on public holidays)



The helpline operates Monday to Friday 8am - 4.30pm (not public holidays). If you experience a problem outside of these hours then attend the emergency department at your nearest hospital. You can leave a message on our answering service and the clinical nurse consultant will be in touch the next working day.

We encourage our patients to contact the helpline so that we can best support you at home in managing chemotherapy associated symptoms. It is important that you ring us early in the day if you have a problem. The nurse will triage your symptoms and organise a treatment plan. You may be asked to come into the Cancer Centre for assessment by the Nurse Practitioner or a medical officer.

It is important that you tell us if you have any symptoms or problems that are worrying you as soon as you experience them so that we can prevent the need for an admission to hospital.

As an example, you may wish to speak to the Cancer Helpline for side effects such as:

- Uncontrolled nausea and vomiting
- Pain
- A sore mouth/mouth ulcers
- Constipation or diarrhoea
- Urinary problems
- Skin rash
- Feeling generally unwell
- General advice and information about treatment

If you experience a temperature of 38 degrees or above you must present to your local Emergency Department for review.

Nurse Practitioner Symptom Urgent Review Clinic

Nurse Practitioner Symptom Urgent Review Clinic (SURC Clinic) is located within the Northern Sydney Cancer Centre (NSCC) at Royal North Shore Hospital. It is run by the Oncology Nurse Practitioner who is able to assess, diagnose and manage symptoms from cancer related treatments and problems. If you are receiving treatment at the NSCC and are experiencing symptoms or have concerns related to your cancer treatment, you can self-refer and book in for a consultation with the Nurse Practitioner.

The Nurse Practitioner works closely with all members of the medical oncology team including: your Medical Oncologist, Medical Oncology Training Registrars, Cancer Helpline Clinical Nurse Consultant, Pharmacists, Cancer Nurse Coordinators, Psychologist, Dietician, Oncology Social Worker and your GP.

We encourage our patients who are receiving treatment at the NSCC to use this service if they are worried about symptoms and want to see a member of the oncology care team.

Enquiries and booking Call the Cancer Helpline on 1800 965 222 M-F 8am-4.30pm or for enquiries call 9463 1380

Palliative care services

At RNSH we have a comprehensive palliative care service for both inpatients and outpatients within the Northern Sydney Local Health District. It is common for people with cancer to be referred to the palliative care team. Palliative care is an approach that improves quality of life of people with life-threatening or serious illness and it also includes care of the patient's family. Palliative care involves identification, assessment and treatment of pain and other problems, in the physical, psychological, social, emotional and spiritual parts of our lives. It is recommended that palliative care be introduced early into your treatment pathway, so that you are well supported every step of the way. Members of the palliative care team include doctors, nurses and social workers. The team can be contacted on T: 9926 7875 or you may contact the Nurse Practitioner on T: 0436 685 490.

Pancreatic Cancer Centre

The Royal North Shore Pancreatic Cancer Centre is a virtual patient centre, providing excellence in care for the patient with pancreatic cancer. The centre is multi-disciplinary and includes surgical, medical and radiation oncological, supportive and palliative care, nursing, dietetic, administrative and executive representatives and all others who provide care for, and work in collaboration with, the patient with pancreatic cancer. The centre not only focuses on providing excellence in care for patients, but also enables research in this area and promotes the work to the wider community, including consumers, clinicians and managers.

Clinical trials unit

The Northern Sydney Cancer Centre offers clinical trials in Haematology, Medical Oncology and Radiation Oncology. These trials range from phase 1 (first in human) to phase 4 expanded access. The best person to refer you for a clinical trial is your treating doctor; if you think you might be eligible please ask your treating team.



Apheresis Unit

The Apheresis Unit performs a variety of therapeutic procedures for patients with haematological, renal, and neurological diseases. Apheresis is a process in which blood from a donor or patient is passed through a cell separator. It uses a centrifuge to separate the blood into its various components which can then be removed or collected, before returning the remaining blood back into the circulatory system. The blood components that can be removed are white blood cells, red blood cells, plasma, granulocytes and platelets. The unit is also a collection centre accredited by the National Association of Testing Authority (NATA) for blood stem cell collection for patients requiring haemopoietic stem cell transplantation.

Plasma exchange

Plasma exchange is a procedure involving the separation and removal of the plasma from the blood in order to remove a disease substance circulating in the plasma. The red blood cells, white blood cells and platelets are returned to the patient, along with a prescribed replacement fluid.

Red blood cell exchange

Red blood cell exchange is an automated procedure that removes the patient's red blood cells and replaces them with healthy red blood cells from a blood donor at the same time. Automated red blood cell exchange may help manage iron overload and sickle cell disease.

Peripheral blood stem cell harvest

Blood stem cells are the cells that form into the cellular elements of the blood (ie red cells, white cells and platelets). They are normally found in the bone marrow and can be collected from the peripheral blood (blood stream) of both healthy donors and patients. The collection occurs after a donor has been given a medication that stimulates the stem cells in the bone marrow to multiply and move into the bloodstream. Once in the bloodstream these stem cells can be collected and stored for later use to treat a range of blood-related cancers (such as lymphoma, myeloma and leukaemia).

What are the potential risks and side effects?

Therapeutic Apheresis is known to be safe and well tolerated. Here are some of the side effects that may occur during your procedure:

- Pain at the needle site
- · Feeling tired or cold
- Low blood pressure
- Dizziness or light-headedness
- Nausea or vomiting
- Tingling in the fingers and/or around the mouth.

These do not occur in every patient. Tell your healthcare provider immediately if you experience any of these symptoms. To make you more comfortable, the nurse may give you calcium tablets or may slow down or temporarily stop the procedure for a short time. You may also be given a blanket to keep your body warm and comfortable. Before receiving treatment, you will come to the unit for a vein assessment and education to understand any related risks.



CHEMOTHERAPY AND RELATED SIDE EFFECTS

Chemotherapy is given to destroy cancer cells. It is given at regular intervals to try to stop the cancer from spreading or progressing further. Chemotherapy has side effects, some mild and others more severe - some of which you may or may not experience. Your doctor will review you at regular intervals while you are receiving treatment.

Intravenous Drip

Chemotherapy delivery can be given in a variety of ways, most commonly through an intravenous drip into a vein. Depending on the treatment this may take about 20 minutes or several hours. Sometimes you may receive chemotherapy over several days. If you are receiving chemotherapy as an outpatient you will attend the outpatient



Chemotherapy Day Unit where you will sit in a chair whilst having treatment. There are limited beds available for patients that require them. If you are receiving chemotherapy as an inpatient you will receive your chemotherapy on the ward, in your regular ward bed.

The nurses will assess you before chemotherapy and monitor you during and after your treatment. They will insert a small tube in your arm known as a cannula. This cannula will stay in for the chemotherapy and then be removed once it has finished. Sometimes it is necessary to put in a tube known as a central venous access device. The purpose of this type of device is that it can be left in your body for the full course of treatment, often for several weeks or months. If this is necessary the nurses will give you information about the specific device that you require. These devices are inserted in the Radiology Department and some types of central lines will require weekly dressings by a qualified nurse. This will be organised by your treatment team.

The chemotherapy nurse will provide you with specific information on side effects and advise you on medications that you need to take when you go home. In addition, you will be given printed information about the chemotherapy drugs that you have been given.

Many patients feel well enough to travel to and from the hospital by themselves. We recommend that for the first chemotherapy appointment that you have somebody accompany you as you travel home.

Other Ways of Having Chemotherapy

Oral chemotherapy: Chemotherapy may be given as a tablet or capsule. Your treatment team will tell you how to take it and how to handle the medication safely.

Chemo-embolisation: Some chemotherapy agents are given via an artery in the groin directly to the liver. This is done under radiology guidance. This method of chemotherapy delivery is known as a chemotherapy embolisation or a TACE procedure. This procedure requires an admission to hospital usually overnight.

Cream: Chemotherapy can be prescribed as a cream which can be applied directly to the skin.

Injections: Some chemotherapy can be injected using a needle into different parts of the body. This may be done into the subcutaneous tissue (the tissue directly under your skin), or into the muscle usually in the buttock or thigh.

Infection covid-19

The recent COVID-19 pandemic has impacted on patients and their families and carers visiting the NSCC. To ensure your safety when you attend the centre you will receive a telephone pre-screening call the day before your treatment or visit to the centre. You will be asked a series of questions about recent travel destinations and your general health i.e. cough, runny nose, fever, sore throat, shortness of breath, changes in your smell. You will also be asked whether you have been on contact with anyone that is a known contact of the COVID-19 virus.

For accurate information about COVID-19 please visit:

Australian Government - Department of Health website:

www.health.nsw.gov.au/Infectious/covid-19

Infection: general Information

During chemotherapy treatment some people can experience low levels of neutrophils. These are white blood cells that help your body to fight infection.

When the number of neutrophils in your blood is low, this is called neutropenia. If you have neutropenia, your body can't fight infection as well as normal. Neutrophils are usually at their lowest level 7 to 14 days after chemotherapy. At this time, you are at greater risk of developing an infection. You can have neutropenia without knowing that you have it so it is important to be careful and pay attention to any signs of infection. Remember you can develop an infection at any time throughout your treatment journey.

Without enough neutrophils to fight infection, infections can become very serious within a matter of hours. Infections that develop when you have neutropenia need to be treated with antibiotics as soon as possible.

Signs of infection

- One important sign of infection is an elevated body temperature.
- This means a temperature of 38C or higher.
- Other signs of infection may include chills, sweats, shivering, body aches and pains or feeling like you are getting the flu.
- You may have a sore throat or feel short of breath.
- You may notice a swelling, redness or tenderness especially around a wound, a catheter site or in your rectal area.
- · Others signs of infection can include diarrhoea
- Or you may experience pain or blood when you pass urine.

If you feel any of these symptoms you need to check to see if you have a fever. You will need to buy a thermometer to check this at home. If you have a temperature of 38C or above, you must go to your nearest hospital emergency department without delay. You can sometimes have an infection without a temperature, so always contact your doctor or nurse if you feel unwell. If you are unsure of what to please call the cancer helpline or present to the emergency department and they will assess your symptoms.



Present to the Emergency Department at the nearest Hospital without delay if you experience a temperature over 38°C or chills and rigors (a violent attack of shivering).

On arrival

It is important that you tell the triage nurse that you have had chemotherapy, immunotherapy or are on any cancer treatment.

At your education orientation you will be given a special neutropenia alert card. You should give this card to the triage nurse on your immediate arrival in the emergency department.

It is important to tell the triage nurse or doctor when you had your last treatment.

Patients often ask is there anything they can do to help raise the neutrophil count and prevent infection. Unfortunately there is nothing that you can eat or drink that will naturally increase or stimulate your bone marrow to make more neutrophils. The neutrophil count will recover on its own usually in a number of days. In certain cases you may be given a hormone injection to boost the number of neutrophils in your body. It is important when you are on cancer treatment that you are vigilant at all times to protect yourself against infection.

This injection known as granulocyte colony stimulating factor (GCSF) is usually given 24 hours after chemotherapy has finished and it is given under the skin on the stomach. Your treatment team will inform you of the side effects that are most commonly associated with this treatment.

Regular blood tests will be done to monitor your white cell count. Your doctor/nurse will tell you how often this needs to be done. If these counts drop excessively, your treatment may be postponed or your dose of chemotherapy may be reduced.



Preventing Infections

How do infections occur?

Infections come from germs from your environment and include bacteria, viruses and fungi. Patients receiving anti-cancer treatments are more at risk of contracting an infection due to a number of factors including chemotherapy drugs lowering the body's immune system.

Germs can enter your body in various ways:

- 1. Breathing in germs for example from people coughing and sneezing.
- 2. Ingesting germs through your mouth when you eat, drink or touch your mouth with your hands.
- 3. Germs can enter through your blood- from a pimple, mouth ulcer, a scratch or an infected cannula site or wound on your body.

There are things that you can do to reduce the risk of infection occurring.

Always wash your hands (preferably from a soap pump pack) or use alcohol hand rub before preparing food, eating and after using the bathroom and after being in public places. Generally good personal hygiene is essential when receiving cancer treatment. This includes showering daily and cleaning your teeth after each meal and before you go to bed. Keep any cuts or scratches clean and report to your treatment team if you are concerned about any skin infections.

- Avoid people with any infection including coughs, colds, respiratory illnesses, diarrhoea, conjunctivitis, cold sores or chickenpox.
- Avoid crowds where possible (e.g. shopping centres, public swimming pools, cinemas and public transport).
- Avoid cleaning up any pet or animal poo.
- Wash and peel fruit and vegetables before you eat them.
- Don't eat raw fish, seafood, meat or eggs.
- Avoid building sites, including home renovations; if required to do so always wear a mask.
- We don't recommend to swim in public pools, rivers, lakes or go to hot tubs.
- Check with your treating doctor before having any vaccinations or dental work.

- Do not use suppositories or enemas.
- Do not use tampons.
- Use a moisturiser such as sorbolene cream to soften and protect your skin.
- Sometimes you may be prescribed preventative antibiotics, antiviral or antifungal medicines as part of your treatment. Ensure that you understand how to take these medicines and don't stop taking them unless instructed to do so.

Please note: Avoid gardening, building sites, cleaning bird cages, cleaning fish tanks, or changing cat litter, all of which can expose you to harmful bacteria.

Presenting for chemotherapy with a cough or cold

In the event that you feel unwell on the day of your treatment you can call the cancer helpline to discuss your symptoms. If you present to the cancer centre with symptoms it is important that you report these symptoms to the front desk on arrival so an assessment can be done. Symptoms may include a cough, cold, runny nose, skin rash, diarrhoea or any type of respiratory infection. If this happens you will be isolated and a medical officer or nurse will perform a clinical examination prior to treatment being commenced. In some circumstances your treatment may be delayed and you may be sent home.

Infection can occur during you cancer treatment at any time. Please do not be afraid, communicate any signs or symptoms you may have to you treatment team or the cancer helpline nurse. In the event that you have a temperature of 38 degrees or above remember you need to present to the emergency department for an urgent assessment.

If you are unsure about infection or have questions please call the Cancer Helpline 1800 965 222.

Bleeding

Some chemotherapy can reduce your bone marrow's ability to produce platelets, which are used in the body to stop bleeding. A low platelet count is called thrombocytopenia.

Regular blood tests will be done to monitor your platelet count. Your doctor/ nurse will tell you how often this needs to be done. If these counts drop excessively you may need a platelet transfusion.

Report to your doctor or the Emergency Department at your nearest hospital if you have bleeding that will not stop.

Signs of low platelet count are:

- Bruising
- Small red spots under the skin (petechiae)
- Bleeding of the gums or when brushing teeth
- Pink or red urine
- Black or bloody bowel movements
- Frequent nosebleeds
- A persistent headache
- Blood shot eye(s)

Avoiding Bleeding Problems

- Do not take any medications containing aspirin (e.g. Aspro Clear®, Solprin®, Cartia® and Cardiprin®) or anti-inflammatory medications (e.g. Celebrex®, Naprosyn®, Nurofen®, Voltaren®) without first checking with your doctor.
- Do not use suppositories or enemas unless prescribed by your doctor.
- Use a soft toothbrush.
- Do not floss your teeth.
- Take extra care not to cut yourself when using sharp implements.

- Avoid contact sports and other activities that might result in injury.
- Use an electric shaver instead of a razor.
- Do not garden due to risk of injury and infection.

If you do bleed, apply pressure for 10 minutes using a clean cloth or gauze dressing and seek help from your treatment team.

Anaemia

Some chemotherapy can reduce your bone marrow's ability to produce red blood cells which carry haemoglobin. Haemoglobin transports oxygen around your body. A low haemoglobin count is called anaemia.

Regular blood tests will be done to monitor your haemoglobin count. As red blood cells carry oxygen to all parts of your body, you may become tired and weak if this count is low. If your haemoglobin count falls very low you may require a blood transfusion.

Signs and Symptoms of anaemia

- Tiredness and weakness
- Easy fatigue and loss of energy
- · Difficulty concentrating
- Shortness of breath
- Light-headedness
- Pale looking skin.
- Usually rapid heart beat

Mouth Care

Some chemotherapy can cause a sore, dry or ulcerated mouth. To prevent infections occurring and promote healing, it is important to keep your mouth clean during your treatment. Brushing your teeth with a soft toothbrush after meals is recommended. Please note that using mouthwash alone does not substitute for brushing teeth after eating.

Suggestions to reduce a Sore Mouth

- Use a soft, small headed toothbrush which must be rinsed well after every use.
- Gently brush your teeth after each meal using circular strokes.
- Use an approved mouthwash at least 4 times a day. Rinse your mouth well, and then spit out.
- Avoid commercial mouthwashes that contain alcohol, as they will dry and irritate your gums.
- If you have dentures, remove and clean them after each meal. Rinse your mouth with mouthwash when your dentures are out.
- Stay well hydrated, and take frequent sips of water to keep your mouth moist.

Mouthwash Recipe

We recommend a sodium bicarbonate or a salt and water mouthwash. Dissolve either 1 teaspoon of sodium bicarbonate powder (bicarbonate of soda) or 1 teaspoon of common salt in a glass of warm water.

Treatment for a sore mouth, ulcers or infections

- If you develop a white coating on your tongue, inform your treatment team for assessment and treatment.
- Biotene® toothpaste may help if other toothpastes irritate your gums.
- Drink plenty of fluids.
- Suck on ice and ice blocks.
- Eat soft, bland moist foods.
- Chew sugarless chewing gum or suck sugarless lollies (these stimulate the flow of saliva).
- Use lip balm regularly.

• If your mouth is very dry, use a mouth-moisturising gel or spray available from any pharmacy (i.e. Biotene®).

Avoid

- Mouth washes containing alcohol (most commercial mouthwashes).
- Spicy and salty food.
- Acidic foods (grapefruit, oranges, lemons and tomatoes).
- Rough, coarse or dry foods.

Pain Relief

- Use Xylocaine Viscous. Sip 5ml slowly, or rub around your mouth.
 Avoid eating hot foods after using this (you will need a script from your GP or treatment team).
- For an individual ulcer use Orabase gel or Xylocaine 2% jelly (from your pharmacy).

Dental Care

If you need dental treatment and are currently having chemotherapy, it is important that you ask your doctor when is the safest time to have dental work.

Bisphosphonates and other bone targeting agents

Some cancers can spread to or affect the bones. This may cause the bones to become weak, release calcium into the bloodstream (hypercalcaemia) and on occasions the bones may break. If this happens your doctor may prescribe a drug from a group of drugs called bisphosphonates to reduce the complications related to the cancer. There are also new drug treatments using monoclonal antibodies that target this problem which may be prescribed by your doctor.

You must see a dentist **before** commencing any treatment with a bisphosphonate drug as it can cause a serious condition called osteonecrosis of the jaw. Osteonecrosis of the jaw is a rare condition causing loss and breakdown of the jawbone It is important to tell your treating doctor and your dentist that you are taking these drugs **before having any dental work done**. It is also important to tell your doctor and dentist immediately if you have pain, swelling or infection of the gums, loosening of teeth, poor healing of the gums and/or numbness or the feeling of heaviness in the jaw.

Nausea and Vomiting

In the past, chemotherapy was associated with nausea, with or without vomiting. However, with new and improved anti-nausea (anti-emetic) medications we are now generally able to prevent this occurring. Anti-nausea medications are often given before and after chemotherapy. These can be given either orally, intravenously, intramuscularly (not recommended for haematology patients) or rectally as a suppository (not recommended for haematology patients).

Anti-nausea medication

The anti-nausea medication you receive will depend upon the type and dosage of chemotherapy that you are given. It is important that you take the anti-nausea medications regularly (at least 30-60 minutes before eating) for at least one or two days after the chemotherapy finishes to prevent nausea and vomiting even if you feel well.

The drugs most commonly used include:

- Ackenzeo® (Netupitant & Palonosetron)
- Aloxi® (Palonosetron)
- Ativan® (Lorazepam)
- Cyclizine
- Dexamethasone
- Emend® (Aprepitant)
- Maxalon®, Pramin® (Metoclopramide)
- Motilium® (Prochlorperazine)
- Olanzapine Zyprexa®
- Stemetil® (Prochlorperazine)
- Sativex® (Medicinal cannabis)
- Serenace® (Haloperidol)
- Zofran® (Ondansetron)

Side effects of anti-nausea medications

Common side effects include drowsiness, difficulty concentrating, headache and constipation.

To prevent constipation it is recommended to take a laxative (eg. Coloxyl) and drink plenty of water. Speak to your treatment team for more advice on prevention of constipation.

Other ways to prevent nausea and vomiting

- Eat small, frequent meals.
- Try dry, salty crackers or toast, cold food (e.g. meats, sandwiches, salad), as these are easier to manage.
- Avoid food with strong odours and cooking smells.
- Avoid preparing food when you feel sick; let someone else help with meal preparation!
- It is important to drink plenty of fluid (e.g water, cordial, lemonade, ice blocks, soup).
- Flat ginger beer, peppermint or ginger tea may help.
- Relaxation techniques may help.
- Acupressure bands (available from pharmacies) may help.

Ask to speak to a dietician if you need further advice on your diet and maintaining your weight.

Go to the closest emergency department for assessment if you have severe nausea or are vomiting more than three times a day to prevent dehydration. Dehydration can cause serious complications if not treated promptly.

Signs of dehydration include headaches, small urine output, rapid heart rate, dry and flushed skin, confusion and dizziness.

It is important that you let your treating team know if you experience nausea that persists for more than two days. Your anti-nausea medication may need to be changed.

Bowel Care

Diarrhoea

Some chemotherapy may cause diarrhoea. Diarrhoea can be defined as in excess of 6 loose bowel motions per day. If you have diarrhoea, take the anti-diarrhoeal medications provided by the treatment team as directed. If anti-diarrhoeal have not been supplied you will need to contact your GP for advice on how to manage this problem.

Treatment of Diarrhoea

- Drink plenty of fluids (e.g. water, cordial).
- Sip small amounts frequently.
- Suck on water ice blocks.
- Do not drink fizzy drinks as they can cause gas and bloating.
- Avoid alcohol, coffee and large volumes of fluid at one time.
- Avoid high fibre foods (e.g. raw fruit, vegetables and cereals), fatty meals, chocolate, dried fruits, beans, nuts and popcorn.
- Eat small meals that have foods high in pectin (e.g. cooked peeled apples, bananas, avocados, rice and toast).
- Stop your laxatives if you are taking them.
- Take anti-diarrhoeals if supplied by your treatment team.

If the diarrhoea does not resolve with anti-diarrhoeal, and you are exceeding six loose bowel motions in 24 hours you should present to the emergency department for assessment.

Constipation

Some chemotherapy, anti-nausea, pain medication and cancer related drugs can cause constipation. This is more likely to occur if you are taking Morphine based drugs, Codeine, Endone®, Vincristine, OxyContin®, Ms Contin®, fentanyl. If you experience constipation for more than two days, let your treatment team know (Cancer Helpline 1800 965 222) so that they can advise you on the best treatment and management of this problem.

Prevention of Constipation

- Drink plenty of fluids, 2-3 litres/day (e.g. water, prune juice and other fruit juices).
- Exercise as able; try to do some light exercise at least 30 minutes a day.
- Eat more high fibre foods, such as wholegrain bread and pasta, bran, fruit and vegetables nuts and legumes.
- Do not use suppositories or enemas unless prescribed by your treatment doctor.
- It is important to take your laxatives as prescribed or seek advice if you are prone to this problem, prior to starting your treatment.

If constipation persists, consult with your nurse, pharmacist or doctor Cancer Helpline 1800 965 222.

Nutrition

While receiving cancer treatments, it is important to eat nutritious foods to help the body cope with treatment side effects. Good nutrition assists with helping the body to heal wounds, improves your body's immune system, helps to reduce fatigue and generally helps you to stay a healthy weight and to feel better in yourself. Eating a well-balanced diet is something that you can actively engage in and it can enhance your quality of life.

Eat a variety of wholegrain, wholemeal and high fibre food such as cereals, breads, rice and pasta. Try to have moderate amounts of lean red meat and limit or avoid processed meat. Choose foods low in salt and low in fat. If you eat a well-balanced diet, with foods from the five basic food groups (vegetables and legumes; fruit; grain (cereal) foods; lean meat, and poultry, fish, eggs, tofu, nuts and seeds; milk, yoghurt, cheese and/or alternatives), scientific evidence suggests that you will cope better with the side effects of treatment.

Nutrition is a booklet produced by Cancer Council NSW and is available in the NSCC Resource Centre. This booklet will provide you with information on recommended nutrition, as well as answers for problems you may be experiencing with your diet. If you need further advice it is important that you tell your doctor or nurse so that a consultation can be arranged with a hospital dietician.

If you would like to learn more about nutrition and cancer you can access some short videos on a number of topics relating to the effects of cancer and treatment on diet. These patient videos have been developed by the hospital dieticians for your information and support:

https://www.nslhd.health.nsw.gov.au/Cancer/Pages/Patient-Carer-Information.aspx

Skin Care

Chemotherapy and targeted cancer treatments can cause problems with your skin which will need to be managed. If you develop any skin rashes or problems with your skin you need to report to your treatment team (Cancer Helpline 1800 965 222).

- Most chemotherapy makes you susceptible to sunburn. Always wear factor 30+ sunscreen a hat and a long sleeve shirt and clothing when outside in the direct sunlight.
- Dry or itchy skin may occur. Use a moisturising cream (e.g. Sorbolene and Glycerin cream or moisturisers containing urea, such as Moo Goo©). Avoid long, hot showers or baths, perfume and after-shave lotion that contains alcohol.
- Acne can be caused by some cancer treatments. Oatmeal based skin cleansers, moisturisers and shampoos can be helpful to reduce inflammation. Avoid skin toners and highly perfumed products as they can cause inflammation and irritation to acned skin. If the acne persists you may need
 - some antibiotics. In some cases your treatment team may make a referral to a dermatologist for management, and treatment may need to be changed.
- Red, sore hands and feet with or without peeling skin may occur. Report this to your treatment team. The area will need specific care and treatment may be delayed.



Nail Care

Separation of nails from the nail bed may occur with some chemotherapy drugs. It is important to keep your nails clean and trimmed and wear protective gloves during cleaning and washing up dishes. A nail hardener is sometimes recommended by your treatment team, depending on the drugs that you may be given. Ensure that this is applied weekly and that you report any signs of nail infections and nail separation to your treatment team.

Some chemotherapy can cause damage to the skin if it leaks out of the vein when it is being administered.
Tell your doctor or chemotherapy nurse if you have any burning, pain, redness, blistering or swelling around the needle site either during or after the treatment has finished.





Nerve Damage

Some chemotherapy may cause numbness and tingling in your hands and feet. Although this side effect may go away in time it is important that you tell your doctor / nurse if it happens. It may be that the doses of your chemotherapy drugs need to be adjusted. With some chemotherapy drugs it is recommended that you wear cotton or rubber gloves if you want to handle hot or cold objects (such as cold cans of drink, ice-cream, hot washing up water). Your treatment team will educate you further about this if required.

Some chemotherapy drugs can affect your hearing. Inform your treatment team if you experience any hearing loss or ringing in the ears (tinnitus). It may be required that you undergo a hearing test prior to starting treatment.

Fatigue

Tiredness can occur because of your chemotherapy and your illness. It is important to maintain a healthy lifestyle to reduce your fatigue and improve your quality of life.

Prevention of Fatigue

- Try to maintain good sleep habits. Avoid sitting up too late at night, avoid sleeping too much during the day, and try to undertake calming activities during the evening before bed.
- Eat a nutritious diet that limits caffeine and alcohol.
- If you are having trouble sleeping, try alternative methods of relaxation such as music and relaxation tapes, acupuncture, yoga, breathing techniques, reading.
- Moderate intensity exercise has been shown to reduce fatigue levels (30 minutes per day).
- Prioritise activities in your day. Do the most important activities when you
 have the most energy. Ask for help with routine activities if you need to
 (e.g. shopping, cleaning and cooking).
- If insomnia becomes a problem, speak to your treatment team or GP.

Hair Loss

Hair loss occurs because chemotherapy targets all rapidly dividing cells – healthy cells as well as cancer cells. Hair follicles, the structures in the skin filled with tiny blood vessels that make hair, are some of the fastest-growing cells in the body. As the chemotherapy does its work against cancer cells, it also destroys hair cells.

Many anti-cancer drugs or chemotherapy drugs will cause temporary, partial or total baldness. Hair loss does not usually happen immediately, but begins within the first 3 weeks after your first treatment. Hair can fall out gradually or more dramatically, in clumps. Some chemotherapy drugs have no effect on your hair, others affect only the hair on your head, some can cause the loss of eyebrows and eyelashes, pubic hair, and hair on your legs, arms, or underarms.

Your hair may also become dry and brittle during chemotherapy. Hair that falls out during chemotherapy will grow back once the chemotherapy treatment has finished. It may take between four and twelve months for the hair to completely



grow back. The texture of your hair may change and it may even be a different colour or become curly if it was straight and vice versa. Over time it usually returns to its normal condition.

Losing your hair can be distressing. This is a normal reaction; remember you are not alone during this time. Family and friends can be a very valuable source of support and your treatment team is always available to provide support and advice on how to cope with this upsetting side effect of treatment.

The Northern Sydney Cancer Centre Resource Centre is located on level 1, just left of the main reception desk and has a variety of wigs available for loan. There is generally no charge, but if you are able, you can make a donation. This money is used to buy more wigs to ensure as many patients benefit from this service as possible. Each wig comes with a care pack including a stand, shampoo and conditioning spray and a wire brush. The Royal North Shore Hospital Cansupport staff and volunteers in the wig library can provide information about wig care and provide information on retail outlets where wigs can be purchased.

Page 36

The Wig Library also has a selection of turbans and beanies that can be obtained for a gold coin donation. You need to make an appointment to be fitted for a wig. The Resource Centre is open 9am – 5pm Monday to Friday or call 9463 1188 for more information.

Suggestions for caring for your scalp and hair

- Use a mild shampoo
- Use a soft hairbrush
- Use low heat when drying your hair
- Don't dye or perm your hair
- Use sunscreen and a hat.



Fertility

For both men and women having cancer treatments, fertility may be impacted. Some chemotherapy can affect your ability to have children. This may be temporary or it may be permanent. It is important that you discuss fertility issues with your doctor before you commence treatment.

Pregnancy can still occur during chemotherapy. As chemotherapy can be harmful to growing babies it is important that effective contraception is always used throughout your treatment.

For males, if permanent sterility is likely, you may consider sperm banking. This means that your sperm will be frozen for future use. This should be done before your first treatment.

For women, fertility preserving treatment options should be discussed with your doctor prior to treatment commencing. Some of the treatment options include egg freezing, embryo freezing and ovarian tissue freezing. Your doctor can give you more information about these options and may refer you to a fertility specialist if requested.

In females, chemotherapy may affect hormone production. Your periods may become irregular or stop completely. Because chemotherapy can affect hormones you may experience menopause-like symptoms (e.g. hot flushes, dry skin, vaginal dryness and mood swings). In some cancers these symptoms can be treated with hormone replacement therapy. However drugs will not restore fertility. It is important that you and your partner discuss fertility issues with your doctor prior to commencement of treatment.

Excretion of Chemotherapy

It usually takes your body one week after treatment to eliminate all the chemotherapy from your body via your body fluids e.g. urine, bowel motions, vomitus, semen and vaginal fluid. Therefore it is important to protect other people, both in hospital and at home, by adhering to the following:

- You should flush the toilet twice on a full flush with the lid down after you
 have used it.
- Carers who need to empty vomit bowls or change wet or soiled beds at home should wear protective gloves to avoid direct skin contact with the body fluid.
- All soiled linen/clothing should be washed in the washing machine on the hot cycle and hung outside to dry.

It is important to protect your partner from your body fluids by using a condom or a female condom if you have any type of sexual intercourse within the week of chemotherapy treatment.

Please also refer to the section in this booklet, 'General Information for all Patients' (page 50), which includes additional advice and information to assist chemotherapy patients in coping with the effects of cancer treatment.

IMMUNOTHERAPY AND RELATED SIDE EFFECTS

Immunotherapy is a type of cancer treatment which helps the immune system to fight cancer. Immunotherapy is different to chemotherapy as chemotherapy directly affects the growth of cancer cells. Immunotherapy uses the body's own immune system to attack and destroy cancer cells.

The human immune system is a complex network of cells, organs and processes which work together to rid the body of pathogens and damaged cells. Cancer can develop when abnormal cells begin to grow uncontrollably. The immune system usually prevents this from occurring by identifying and destroying abnormal cells. Occasionally the immune response is not strong enough to kill all the abnormal cells and this develops into cancer.

Cancer cells can also develop and produce signals which stop the immune system from recognising and attacking it. Immunotherapy works to allow the immune system to recognise these cancer cells and target an immune response.

Immunotherapy is most commonly delivered through the vein. If you are receiving immunotherapy as an outpatient you will attend the outpatient cancer centre and receive the treatment while sitting in a chair.

Prior to receiving immunotherapy treatment the nurse caring for you will complete an assessment. This involves the nurse asking a series of questions about side effects. It is important to report any side effects or concerns to ensure you are being managed safely. The nurse will also review your blood test results prior to commencing treatment. It is essential that you have a blood test 1-2 days prior to treatment to monitor your tolerance to immunotherapy.



Immune Related Adverse Events

Immunotherapy unlocks the body's natural safeguards being immune checkpoints which prevent an overactive immune system. However this can lead to the immune system targeting normal tissues leading to immune related adverse events.

Immune related adverse events typically occur early during treatment usually in the first weeks to three months after treatment has commenced. Most adverse events are mild to moderate and if detected early and appropriately managed.

Common side effects

- Fatigue
- Changes in weight and temperature
- Skin rash and itch
- Diarrhoea and abdominal pain
- · Pain in the joints

If you experience any of these symptoms please report them to your doctor and treating team

Rare side effects

- Headaches, visual changes
- Breathlessness, coughing
- Excessive thirst
- Yellowing of the eyes, severe abdominal pain and dark urine

Report to your doctor or the Emergency Department at your nearest hospital if you experience any of these symptoms

For more information about immunotherapy and immunotherapy side effects please see the following link from the Peter MaCallum cancer centre.

www.petermac.org/services/cancer-information-resources/videos-whatexpect-immunotherapy

TARGETED THERAPY

This is a type of drug treatment that works by specifically targeting certain features of cancer cells. These drugs have been approved for use in Australia for a variety of different cancers including bowel, breast, cervical, lung, ovarian and thyroid cancers. Targeted therapy is also indicated for melanoma, some types of leukaemia, lymphoma and myeloma. These treatments may be given by injection into the vein, injection into the subcutaneous tissue or taken as an oral tablet. The drug therapy circulates throughout your body and works on specific molecular targets within or on the surface of cancer cells. These molecular targets are involved in how cancer cells grow and replicate. The drug interferes with this process and destroys cancer cells whilst at the same time minimising damage to healthy cells in your body.

Targeted drug therapy works differently to chemotherapy. The drugs are more cell specific than traditional chemotherapy and therefore the side effects are different. Targeted therapy can interact with other medicines so it is important that you tell your doctor if you are taking any other medicines.

Targeted therapy is generally well tolerated and the symptoms may vary from person to person and depending on what drug you are receiving. Your doctor and nurse will give your drug information about your specific drug treatment and discuss with you some of the common side effects you may experience. Below is a general list of common side effects from targeted therapy.

Common symptoms from targeted therapy include

Skin problems including:-

- Rash, sun sensitivity, swelling and dry flaky skin.
- A skin rash that looks like pimples or acne on the face scalp or body.
- A skin reaction on the palms and soles causing tenderness and blisters.

Other symptoms include

- Fever
- Tiredness
- · Joint pains
- Nausea

- Headaches
- Diarrhoea
- · Heavy bleeding and bruising
- · High blood pressure

Managing Side Effects from Targeted Therapy

Your health care team will regularly monitor your side effects from treatment. Side effects from treatment can start within days but more commonly they occur weeks or even months later. Let your treatment team know if you experience any side effects from treatment. Sometimes the doses of the drug may need to be adjusted to reduce symptoms and side effects.

Targeted drugs can have serious side effects including heart and lung complications so it is important to alert your nurse or doctor if you have any symptoms.

If you are an oncology patient receiving targeted therapy experiencing symptoms, you can request an appointment in the Nurse Practitioner Symptom Urgent Review Clinic (SURC Clinic) by calling T: **9463 1380**

Alternatively you can call the Cancer Helpline 1800 965 222 to request an appointment with the Nurse Practitioner.



RADIOTHERAPY AND RELATED SIDE EFFECTS

Radiotherapy uses radiation in the form of high energy x-rays, gamma rays, electron beams or protons to treat cancer. The high dose radiation kills cancer cells by stopping them from growing and dividing. When radiotherapy is given, side effects may occur due to damage to surrounding healthy tissues at the treatment site. The side effects you experience will depend on the part of your body and the size of the area that is being treated.

Radiotherapy can be given using an external beam treatment where a machine directs its beam towards the cancer from the outside of the body. It can also be given internally by being placed inside the body on or near the site of the cancer.

Side effects are usually temporary and should start to improve within a few weeks of finishing treatment. The information detailed below will explain how to prevent and manage the most common radiotherapy side effects. Your nurse or radiation therapist will discuss the side effects which may be experienced at the beginning of your treatment. You will be reviewed on a weekly basis, so please inform your doctor, nurse or radiation therapist if you are experiencing side effects that are worrying you.

Skin Care

A common side effect of radiotherapy is a change to the skin in the area you are having treated. Skin changes occur because radiotherapy can damage healthy skin cells within the treated area. Looking after your skin during radiotherapy is very important.

During radiotherapy, the skin surrounding the area being treated may

- · Become pinker than normal
- Become red (similar to sunburn)
- Feel warm to touch
- Become sore and sensitive
- Become dry and flaky
- Peel, blister or weep

The effects of radiotherapy to your skin usually occur about 2-3 weeks after your first treatment and continue to progress over the duration of the treatment. Most skin changes will resolve within 6-8 weeks after your treatment finishes.

Do's and don'ts

It is important that you adhere to the following:

- Check with your treating team before using any creams or other products on the skin in the treatment area.
- Use Sorbolene cream recommended by the hospital for use on skin during radiation treatments.
- Do not use any creams for **2 to 3 hours before** treatment.
- Stop using creams at the first sign of skin breakdown until the area has been reviewed.
- Do not scratch the skin (if your skin becomes itchy, speak to your doctor or nurse about a cream that may help to relieve the itch).
- Do not use hot packs directly on the treated skin.
- Avoid using adhesive tapes on the treated areas.
- Report any areas of broken skin or blisters to your treating team.
- Gently bathe using warm water and a mild unscented soap.
- Do not rub the skin in the treatment area; pat dry with a soft towel.
- Use only unperfumed moisturisers in the treatment area (e.g. Aqueous cream or Sorbolene).
- Do not attempt to wash off any skin markings (these will fade and can easily be replaced by the radiation therapist).
- Do not use products that contain alcohol or metal in the treated area (e.g. Deodorants, perfumes/aftershaves).
- Do not use sunblock.
- Do not use corn-starch.
- Do not use talcum powder/baby powder.
- Do not use hair removal cream or wax the treated area or pierce the treated area.

Soothing the skin

Applying a cold compress may help to reduce the heat and soothe the affected skin in the treatment area. A cold compress can be made using a clean washcloth or sterile pad soaked in chilled boiled water. Wring out and place in the refrigerator in a zip lock bag for 10-20 minutes then apply to the affected area. Repeat as needed. Ask your nurse for other suggestions if these do not provide any relief.

Sunscreen

Protect your skin from the sun and wind by using sunscreen (SPF 30+) and covering up.

(Note: do not apply sunscreen in the treatment area while you are having radiotherapy).

Once your radiotherapy treatment is completed and your skin has healed, protect your skin by using sunscreen (SPF 30+) and covering up while in the sun and wind). Your skin can remain sensitive for a period of time after your treatment has been completed.

Swimming

Discuss swimming with your doctor or nurse. In most cases, you will be allowed to swim in salt water during treatment. However, you should avoid swimming in chlorinated pools as the chlorine may irritate and dry the skin in the treated area. If your skin starts to shows signs of peeling, blistering or weeping, it is advised that you stop swimming due to the risk of infection and skin problems.

Diarrhoea

Diarrhoea is a common side effect of radiotherapy to the abdomen or pelvis. You may notice a change in bowel habits starting 1-2 weeks after your radiotherapy commences. You may notice an increase in how frequently you open your bowels, and your bowel motions may be more watery than usual.

Strategies to manage diarrhoea include the following:

• Limit high-fibre foods in the diet (wholegrain cereals, raw fruits and vegetables, nuts and seeds).

- Increase intake of oral fluids up to 2-3 litres per day; water, sports drinks, weak cordial and broths are the best choices.
- Avoid spicy and greasy foods.
- Limit milk intake but small amounts of cheese and yoghurt are ok.

Medications

- Loperamide (Brand names: Gastro-stop® or Imodium®) can be obtained from the radiotherapy department. The usual dose is 2 capsules with the first loose bowel motion, and one capsule with each subsequent episode of diarrhoea. Maximum 8 capsules daily.
- Lomotil® can be obtained via a prescription from your GP or radiotherapy doctor.

Please speak to your treatment team (doctor, nurse or radiation therapist) if you are experiencing diarrhoea. You should seek immediate medical attention if you have more than 6-8 episodes of diarrhoea in a 24-hour period.

Mouth Care

If you are having radiotherapy to the head or neck region, your mouth will need extra care and attention during this time. It is vital that you commence a basic mouth care routine from the first day of treatment.

This involves the following:

- Gently brush your teeth after each meal using a soft toothbrush.
- If you have always flossed your teeth continue to do so. If you have not
 previously flossed do not start during treatment. Check with your doctor or
 nurse about flossing.
- Rinse your mouth after brushing and flossing at least 4 times per day using a
 mouthwash given to you by the hospital. Otherwise use a warm salt water or
 sodium bicarbonate mouth rinse, such as
 - 1/2 teaspoon of salt to one glass (200ml) water OR
 - 1 teaspoon of sodium bicarbonate (baking soda) to one glass (200ml) water.

Page 46

- · Keep your lips moist by frequently applying lip balm.
- If you have dentures, remove and clean them after each meal.

 Rinse your mouth with mouthwash when your dentures are out.
- Do not smoke or drink alcohol as they can irritate the mouth.

Dry mouth

Radiotherapy to your head and neck can affect the salivary glands which produce the saliva in your mouth. The decrease in saliva can make your mouth and throat dry and make it difficult to eat and talk.

How to manage dry mouth symptoms:

- Take frequent sips of water or suck on ice blocks.
- Use a water spray bottle to wet your mouth.
- Chew sugarless chewing gum.
- Suck sugarless Iollies.
- Moisten foods with gravies and sauces.
- Avoid coffee, alcohol, cigarettes and soft drinks which may cause further dryness and speed up tooth decay.
- Dry mouth sprays and gels are available from pharmacies.

Medications

The following medications may be used for mouth problems:

- Xylocaine Viscous is a pain-relieving gel that may be used before each meal to help make eating easier. You can obtain this by speaking to the nursing staff and they will organise a prescription.
- Nystatin drops® are prescribed if you develop a white coating on your tongue, which is a sign of a fungal infection.
- Soluble paracetamol: 2 tablets up to four times daily can be helpful to relieve pain. Avoid taking asprin, unless prescribed by your doctor.
- Stronger pain medications: please speak to your nurse if you have pain that is unrelieved by paracetamol. You may require a prescription for some stronger pain medication.

How to manage a sore and painful mouth

If your mouth becomes too sore to brush your teeth, there are some things you can do to help your mouth feel better:

- Increase the frequency of the mouth care, you may need to do this every couple of hours.
- Take regular pain relieving medicine as advised by your doctor.
- If you wear dentures, leave them out and only use them for meals.
- Modify your diet to soft foods or liquid to reduce pain when eating.
- Avoid spicy foods and alcohol as they may irritate your mouth.

If you are finding it increasingly difficult to eat, and if you are losing weight, inform your treating team as they will be able to assist you with pain control and may refer you to see a dietician.

Note: It is important to tell your dentist you have had radiotherapy to your mouth. Any invasive dental work (such as extractions or root canal treatment) should be avoided during your radiotherapy treatment. Speak to your radiation oncologist if you are unsure.

Nausea and Vomiting

Patients having radiotherapy to either the lower chest, abdomen or certain areas of the brain are at risk of nausea and/or vomiting. Depending on the a rea you are having treated, your doctor may prescribe some medication to take prior to each treatment. It is important that you take this medication,

even if you don't feel sick.

If you experience nausea and/or vomiting associated with your radiation treatment, you will be prescribed some anti-nausea medication.

For more information about managing nausea and vomiting, see page 28 in the chemotherapy section of this booklet. In addition, the Cancer Council booklet entitled Nutrition has some very helpful tips and information.

Hair Loss

Generally your hair will not fall out. Radiation therapy only causes hair loss on the particular part of the body treated. For example, if radiation is used to treat the breast, there is no hair loss on your head. Radiotherapy only causes hair loss or thinning if there is hair within the treated area, such as your head or neck. This means that only those with cancer in the brain, skull or scalp will experience hair loss on their head. If it does fall out, it will usually grow back over the following month.

The Northern Sydney Cancer Centre Resource Centre is located on level 1, just left of the main reception desk and has a variety of wigs available for loan as well as a range of new turbans and beanies to assist you whilst you are experiencing hair loss. The Royal North Shore Hospital Cansupport staff and volunteers in the wig library can provide information about the different headwear options, coping with hair loss as well as wig care.

Radioactivity

Please note that external beam radiotherapy will not make you radioactive and it is safe to be around other people including pregnant women and children.

If you are having brachytherapy, you may be radioactive for a while after you have treatment. Speak to your treatment team about this and what precautions you need to take. There is information available on this topic from the NSW Cancer Institute website **www.eviq.org.au**

For brachytherapy Patient information - Cervical cancer - Brachytherapy | eviQ

For Radiation treatments Radiation therapy treatments | eviQ

There is a comprehensive booklet on Sexuality, Intimacy and Cancer from the Cancer Council NSW that provides more detailed information on this topic. This booklet is available from the NSCC Resource Centre, level 1 of the Acute Services Building, RNSH.

Total Body Irradiation (TBI)

Total Body Irradiation is used in conjunction with high dose chemotherapy as part of the preparation for a blood stem cell or bone marrow transplant. It involves radiation therapy to the whole body using high energy x-rays.

Short term side effects of TBI treatment are similar to the side effects listed above. It is important to remember that most side effects are temporary, and can be treated. In addition, TBI may cause some longer term side effects. It is important that you discuss any questions with your treating team.

Please also refer to the section in this booklet, General Information for all Patients (page 50), which includes additional advice and information to assist radiotherapy patients in coping with the effects of cancer treatment.



GENERAL INFORMATION FOR ALL PATIENTS

Exercise

Healthy eating, regular exercise and maintaining a healthy body weight are recommended by Cancer Council NSW. Current evidence suggests exercise is beneficial for most patients that are receiving cancer treatments. For more information on exercise please see the Cancer Council NSW booklet Exercise for People Living with Cancer available in the NSCC Resource Centre. Exercise has been shown to assist with many of the side effects of cancer treatments including fatigue, nausea, loss of appetite, depression, anxiety and body weight. Exercise should include at least 30 minutes of moderate-intensity exercise (walking) on most if not every day of the week. You can achieve this by doing three 10 minute sessions a day. If you are suffering from anaemia, fever or severe weight loss you will need to speak with your treatment team prior to commencing exercise.

There are a variety of exercise programs that are available for cancer patients, which are run by exercise professionals. Before taking part in any exercise program it is recommended that you talk with your doctor about any precautions that you should take and whether you are able to participate in the program.

Smoking and Cancer

If you smoke, use e-cigarettes or vapes, it is recommended that you stop smoking. Research evidence suggests that patients receiving cancer treatments do better if they are not smoking during cancer treatment. For more information on the benefits of not smoking during treatment, speak to your doctor or look up **www.icanquit.com.au** or **call the QUITline T: 137 848** to request assistance in giving up smoking and to request a free Quit pack.

Intimacy and Sexuality

Chemotherapy should not permanently affect your sexual performance or ability to enjoy sex. Whatever type of treatment you are having, you and your partner may have temporary problems, most notably a lack of desire due to fatigue, anxiety or just because you feel unwell. Partners may also feel uncertain about having sex as they may fear hurting you in some way. Speak to your treatment team if you need advice on changes in your sexuality and how to communicate this with your partner.

The comprehensive *Sexuality, Intimacy and Cancer* booklet from the Cancer Council NSW provides more detailed information on this topic. This booklet is available from the NSCC Resource Centre, level 1 of the Acute Services Building, RNSH.

Fertility and Cancer

There is a comprehensive booklet on Fertility and cancer from the Cancer Council NSW that provides detailed information on this topic. This booklet is available from the NSCC Resource Centre, level 1 of the Acute Services Building, RNSH. There are additional resources on fertility for young people with cancer available also in the resource library from Canteen Australia www.canteen.org.au

Medication Safety

The clinical teams in the NSCC are committed to ensuring that all medicines, blood product administration and therapeutic treatments are given safely and in compliance with the law. As a patient you will be asked to confirm your details including full name, date of birth and where you live prior to medicines being given to you. You will also be asked about any allergies that you may have to medications or other things. It is important that you tell us if you have commenced any new medication whilst you are receiving cancer treatment.

For information about medication safety please see these useful links below:

Blood resources: www.blood.gov.au/patients

Consent

Before undergoing any treatment or procedure your clinician will ask you to provide consent.

If you are unable to give consent a "person responsible" will be asked to provide consent on your behalf. You may be able to provide consent even if you are a child or young person but you will need to talk with your health professional first.

It is your choice to give consent freely and you have the right to change your mind at any time. Please speak with your Doctor, nurse or health practitioner if you have any concerns.

Consent can be requested verbally, in writing or can be implied, for example by extending your arm out for a blood test. Your clinician should explain things to you in a way that you can understand. Medical treatment is often complicated and you may receive information you don't understand. You are encouraged to ask questions if you do not understand something.

Interpreters are available if needed.

These are questions you may wish to ask:

- What condition do I have?
- What treatments are you suggesting?
- What are the risks and possible side effects for each option?
- Can I seek a second opinion and are there any alternative treatments?
- What drug will be given, what do they do and are there any side effects?
- What should I expect to happen?
- How long is my consent valid for?

Preventing a Fall in Hospital

Falls in hospital can be serious as they can lead to injuries and a longer hospital stay. The following information will help reduce the possibility of a fall occurring whilst you are visiting the Chemotherapy Day Unit or if you are being treated as an inpatient in the general ward areas.

If you are an inpatient the staff will complete a checklist with you or your carer to see if you are at risk of falling. The checklist includes your ability to walk, what medications you take, any history that you may have of falling, your eyesight, memory and thinking problems, and your bladder and bowel habits. You will be supplied with a pair of non-slip socks to wear during your admission to hospital, to reduce slipping on the floor surfaces when mobilising around the ward.

If you are visiting the Chemotherapy Day Unit and you and your family are concerned about you falling, please do not hesitate to speak to your treatment nurse. You may need to be moved to a treatment chair that is closer to the bathroom and easier for you to access.

Visitors to the Chemotherapy Day Unit and the inpatient wards can help by making sure that the area around the patient is clear from clutter. The nurse call bell should always be easy to reach and any chairs or equipment should be put out of the way, to avoid tripping over. Please ask for assistance if required.

Inpatients/outpatients checklist for carers and relatives

- 1. Wear well fitting, non-slip shoes, hospital approved non slip socks or slippers.
- 2. Wear your usual glasses.
- 3. Bring in your usual walking aid if required.
- 4. Wear your hearing aid and make sure you have spare batteries (if you are an inpatient).
- 5. For inpatients, provide nightwear that is above the ankle in length.

Tips to prevent a fall in Hospital

- 1. Use your call bell and keep it in easy reach.
- 2. Take your time when getting up from sitting or lying down.
- 3. Let staff know if you are feeling unwell or unsteady on your feet.
- 4. If unsteady, ask for assistance to get out of the bed or chair.
- 5. Do not grab onto anything unstable.
- 6. Wear supportive shoes, no thongs.
- 7. Keep your walking aid within reach.
- 8. Watch out for spills or obstacles.
- 9. Do not walk in surgical or TED stockings without shoes or non slip socks.
- 10. Night wear should be above the ankles.
- 11. Wear your glasses if needed.
- 12. Sit down to shower and use the rails to get off the chair or the toilet.
- 13. If you feel unsafe in the bathroom remain seated and call for help.
- 14. If you do have a fall, do not get up on your own.

Useful Websites

The internet has an enormous amount of information on cancer and cancer treatments. Some websites are not always reliable and may lead to misinformation which can be distressing. We have included a list of websites that are recommended by the Cancer Council of Australia.

Australian websites

- EVIQ: Cancer Treatments Online is a free NSW Government resource of evidence based information about cancer treatment and related side effects – www.eviq.org.au
- Cancer Council Australia offers a range of information and services to help people with cancer www.cancer.org.au
- Cancer Australia www.canceraustralia.gov.au
- Cancer Council Connect: www.cancer.org.au/support-and-services/ support-groups/cancer-connect
- Clinical Trials Australia www.australiancancertrials.gov.au
- Clinical Trials app available from the app store https://clintrialrefer.org.au/
- Targeting Cancer Radiation Oncology www.targetingcancer.com.au
- Carers Australia www.carersaustralia.com.au
- Department of Health and Aged Care www.health.gov.au
- Canteen is the National Support organisation for young people aged 12-24 living with cancer, children of people with cancer and siblings of people with cancer – www.canteen.org.au
- Exercise -
 - www.abc.net.au/catalyst/exercise-and-cancer/11016526
 - www.cancercouncil.com.au/cancer-information/living-well/exercise-cancer/
 - www.exerciseismedicine.com.au/wp-content/uploads/2020/04/EIM-FactSheet_General-Cancer_Public-2020.pdf
- Northern Sydney Carer Support service -
 - https://www.nslhd.health.nsw.gov.au/Cancer/Pages/Patient-Carer-Information.aspx
 - Or see our Carer Support Information at https://www.nslhd.health.nsw.gov.au/carer/Pages/default.aspx
- Can Revive is a non profit organisation to support Chinese speaking people living with cancer – www.canrevive.com
- Smoking Quit Helpline for information on how to quit smoking www.icanquit.com.au
- Australian Centre for Grief and Bereavement www.grief.org.au
- Lifeline, a general telephone counseling service www.lifeline.org.au
- Black Dog Institute www.blackdoginstitute.org.au

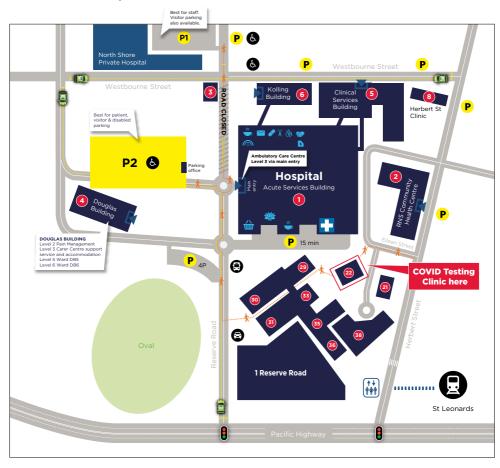
Resources for adolescents and young adults

- Canteen www.canteen.org.au
- Stupid Cancer www.stupidcancer.org
- Livestrong www.livestrong.org/we-can-help/young-adults
- Look Good Feel Better www.lgfb.org.au
- Cancer Council www.cancer.org.au/clinical-guidelines/cancer-fertilitypreservation
- Leukaemia Foundation online education and support www.leukaemia.org.au/how-we-can-help/support-groups
- Sydney Adolescent and Young Adult Cancer Services –
 www.cancer.nsw.gov.au/about-cancer/types-of-cancer/general-cancer-information/finding-support/support-for-young-people
- Beyond Blue supports young people suffering from depression, anxiety and other mental health problems – www.youthbeyondblue.com
- Young Carers (Australia) www.youngcarers.net.au
- My Parents Cancer www.myparentscancer.com.au
- Reachout www.au.reachout.com
- Redkite www.redkite.org.au

International websites

- American Cancer Society www.cancer.org
- Macmillan Cancer Support www.macmillan.org.uk
- National Cancer Institute www.cancer.gov
- Chemo care www.chemocare.com
- Rip Rap www.riprap.org.uk

Visitor Map





Emergency

Bus

Taxi

Lift to train

P2 Carpark - main

& Carpark - disabled

P Carpark - meter

Pedestrian entry

ACKNOWLEDGEMENTS

This booklet has been developed by the Northern Sydney Cancer Centre at Royal North Shore Hospital. Thanks to all the people that reviewed the booklet and contributed to the content:

- Professor Alexander Engel, Clinical Director, Cancer & Palliative Care Network, Northern Sydney Local Health District
- · Professor Michael Back, Head of Department Radiation Oncology, RNSH
- Associate Professor Chris Ward, Staff Specialist Haematology, RNSH
- Rowena Broadbent Nurse Manager NSCC RNSH
- Meredith Oatley, Medical Oncology Nurse Practitioner NSCC, RNSH
- Julija Sipavicius, BMT Nurse Practitioner RNSH
- Stephanie Smith, Clinical Nurse Consultant Medical Oncology, RNSH
- Helen Westman Cancer Nurse Coordinator, RNSH
- Jennifer Arena Pancreatic Cancer Nurse Coordinator RNSH
- Yvonne Gonet, Clinical Nurse Consultant Haematology, RNSH
- Cassandra Reid, Bone Marrow Transplant Clinical Nurse Consultant, RNSH
- Simone Ray, Clinical Nurse Educator NSCC, RNSH
- Rohan Ashover, Nurse Unit Manager NSCC, RNSH
- Nicola Guy, Manager, Cancer Support Services NSLHD, Cancer and Palliative Care Network
- Nancy Burley, Volunteer Cancer Support Services NSCC, RNSH
- Niamh Dempsey. Clinical Nurse Consultant Cancer Helpline NSCC. RNSH.
- Berchi Pranada, Administrative officer NSCC, RNSH
- Rebecca Needham, Cancer Care Coordinator Immunotherapy NSCC, RNSH
- Noni Ferrer, Clinical Nurse Consultant Apheresis NSCC, RNSH
- Paula Macleod Cancer Care Coordinator Head & Neck

Consumer review

Kathryn Jenkins - Clinical trials and patient consumer

Angela Grant - Patients consumer

We also would like to acknowledge the Cancer Council NSW as a source for some of the information included in the sections about sexuality and intimacy, fertility, nutrition and exercise for the cancer patient.

This information has been updated in 2020 with consumer consultation as per *National Safety and Quality Health Service Standard two: Partnering with Consumers.*

Notes	
	_
	_
	_
	_
	_
	_
	_
	_
	_
	_
	_



