

# EMBRACING YOUR JOURNEY.

This is a **Comprehensive Companion to Breast Cancer Treatment and Recovery.** Our compassionate guide gives you an **understanding of the various treatment procedures**, helps you to prepare for it, and **take care of yourself** after recovery.

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## THIS IS A HEALING JOURNEY



You are not alone. And even though this mountain feels impossible to climb, this too will one day lie behind you. Our wish for you is that you get to know your strength and courage on this journey of learning more about your inner strength. Because darling, you are strong and courageous, even if you can't see or feel it now.

This is a healing journey. Yes, it is hard, and yes how we all wish this were not necessary. But if we remain open, curious, and brave, there is so much more to discover beyond what we think and feel right now.

Take a deep breath and know that you can do this.

#### From all of us at Project Flamingo

### WORDS OF WISDOM

"The breast cancer journey is unique for every patient. Every person and every cancer is different. This enables us to target and treat it with much greater success and should encourage patients to know that hope is everpresent, the cure is possible, and above all, that they can play an active role in their healing."

Dr Liana Roodt, Breast & Endocrine Surgeon, Founder and Chair of Project Flamingo

"Instead of asking "Why me?", I have learned to ask "Why not me?" Moving from feeling like a victim of circumstances outside of my control, I have discovered my strength. This journey is all part of the human experience and has put me on a wonderful path of discovery and recovery. As someone standing on the other side of this mountain, I can say that I have not just survived, but thrived!"

Michelle Rennie, Breast Cancer Survivor, Director of Project Flamingo

"Healing represents an expansion of conciousness and a movement in the direction of wholeness and health. We can be healed by our illness but not cured of it. Or we can by cured of our illness but not healed by it. Healing may or may not result in cure."

Dr Maria Christodoulou, Medical Doctor & Integral Health Coach

## **MY** PERSONAL SPACE

#### **TAKING CARE OF YOURSELF**

This is a courageous journey. In the pages that follow, you'll find a space to express your emotions, reflect on your experiences, and draw strength from the power within. It is here to remind you that you are not alone and that your resilience shines brightly, even in the face of challenges.

#### GRATITUDE

Cultivating gratitude and positivity can be a powerful force in navigating through difficult times. **Celebrate the small joys and let them light up your path.** 

Write down some of the things you are grateful for at this moment.



#### Allow this to be a safe space for expressing your emotions.

By acknowledging and processing your feelings, you're taking important steps towards healing.

#### Write down what you feel in these moments.

**MY FEARS & ANXIETY** 

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#### "Joy and pain, they are but two arteries of the one heart that pumps through all those who don't numb themselves to really living."



#### **GENERAL INFORMATION | SELF CARE**

### THE 10 PRINCIPLES OF DELIBERATE LIVING

This healing journey is the ideal opportunity to get more intentional about how we live our lives. These principles have also been shown to improve the general outcome and quality of life of cancer patients. Healing, rather than just cure, is the objective and can have a profound impact on the rest of your life.

#### **#1 SLEEP (REST & REJUVENATION)**

Countless scientific studies are proving the absolute importance of good quality sleep and rest. It is our body's natural way to repair. Try to get at least 8 hours of sleep every night. Taking a hot bath or shower before bed, keeping your room as dark as possible, and using soothing scents and sounds may all aid in a better night's sleep.





#### **#2 MORNING ROUTINE (RITUAL/MEDITATION)**

Wake up and set a clear intention for your day. Before you get busy with your schedule, set aside a few minutes for prayer or meditation to start your day calmly. Make sure you name at least 3 things you are grateful for as gratitude has been proven to be a powerful healing tool.

#### **#3 EATING (MINDFULLY)**

Food is medicine. Try to increase your intake of healthy greens and vegetables and avoid processed and refined food. Try to enjoy eating as a ritual and a privilege no matter how simple the meal.





#### #4 MOVEMENT (STRETCHING & WALKING)

Movement can help you healthily reconnect with your body. Your body needs your love and acceptance to heal and repair. Gentle movement also stimulates energy and helps us manage stress and anxiety.



#### **#5 GETTING RID OF NEGATIVE EMOTIONS**

Running away from negative emotions is bad for our long-term health. It is important to recognize and name those things that make you angry, sad, anxious, lonely, and depressed. Find a friend that you can share this with or journal about it. Make the changes necessary to avoid the things in your life that continue to trigger these emotions. Look at these emotions with love, kindness, and grace for yourself.

#### **#6 FIND JOY**

Make space and time for those things that give you joy. It can be anything - from sharing a meal with those you love to rediscovering a hobby like knitting, reading, gardening, singing, or art. Joy increases our feel-good hormones that can have a positive impact on our immune systems and ability to heal.



#### **#7 SPIRITUALITY**

Making time for your inner space is crucial. A spiritual practice can include religion or simply connecting with yourself. It has been shown that patients with any form of spiritual practice usually benefit greatly from this during a healing journey.

#### **#8 CURIOSITY**

Staying curious about yourself, those you love, and the world around you helps to connect you to a purpose for healing and living. We can learn from even the hardest of times and create meaning and purpose from all that we experience in life.



#### **#9 SERVING OTHERS**



Doing something, no matter how small, helps us to forget about our own troubles and reminds us of our ability to do good in this world. Your gifts are unique and sharing them is a privilege that will bring you joy and healing.

#### **#10 WHOLEHEARTED LIVING**

Manage your time wisely, engage in things that bring you joy, try to be present in every precious moment, and be your beautiful and unique self. Bringing your whole self and heart into the world is a healing gift to yourself and others.



## UNDERSTANDING YOUR DIAGNOSIS

Breast cancer isn't just breast cancer. But rather like a family that all has the same surname but very different names and personalities. Like in all families, some are nice and easy to deal with while others may be more unpredictable and slightly more challenging to manage. This makes breast cancer a complex disease, and everyone's experience is unique. If we understand your cancer's personality, it helps us to decide what treatment would be most effective in managing it.

**Breast cancer treatment is never just one thing** but rather the best combination of a few things (think of it as a treatment basket). This knowledge has vastly improved the cure rate for breast cancer. Breast cancer is now one of the most curable cancers, especially if we combine all the right treatments and in the right order.

### HOW DO WE DETERMINE A BREAST CANCER'S BIOLOGICAL PERSONALITY?

This is why your biopsy is so important as our pathologists spends a lot of time to figure out exactly what makes your cancer grow. The main things we look at is:

- ER Status: How sensitive it is to estrogen (female hormone)
- PR status: How sensitive it is to progesterone (female hormone)
- If it has a special growth receptor called Her2Neu
- How fast the cells are dividing (growth rate) and if it is expressed in a percentage called the Ki67%
- Androgen Receptor Status: For some cancers, we may also test how sensitive it is to androgen (male hormone).



#### "NOT-SO-NICE" PERSONALITY HER2-POSITIVE BREAST CANCER

These cancer cells overproduce a protein called HER2Ney. Some of them may also be sensitive to estrogen and progesterone and others not. They tend to have higher cell division rates and are considered slightly more aggressive. This is why chemotherapy may be recommended before surgery for this type of breast cancer. The chemotherapy should ideally also be combined with a special drug that targets the Her2 receptor but this may not be available at all hospitals and chemotherapy alone is used instead. Once chemotherapy is completed, surgery will be performed and may or may not be followed by radiation.

#### "SOMETIMES-LAZY-OR-SNEAKY" PERSONALITY HORMONE RECEPTOR-POSITIVE (ER/PR POSITIVE) BREAST CANCER

The "lazy" cancers are called Luminal A cancers. They are very sensitive to hormones and have a slow growth rate. A hormone blocker tablet will be started and surgery will be planned. Most of these cancers only need the operation (with or without radiation depending on the type of operation) and hormone blockers as treatment. The "sometimes sneaky" cancers are called Luminal B cancers. They are also very sensitive to hormones but have a higher growth rate. A hormone blocker tablet will be started and surgery will be planned but some of these cancers will also require chemotherapy before or after surgery. It will be different for each patient depending on many factors.

#### **"NASTY" PERSONALITY** TRIPLE NEGATIVE BREAST CANCER



Cells lack sensitivity for hormones and HER2 and often have a high cell division rate. This makes them particularly tricky to target but luckily they often respond well to chemotherapy which is why this is a crucial first step in treating them. This will then be followed by surgery (and sometimes radiation). A small number of patients will also require different type of chemotherapy after the



#### WHY SURGERY ALONE IS NOT ENOUGH

Many patients struggle to understand why just removing the cancer with surgery is not enough to cure it. Many years ago, doctors also did not realise that an operation alone is not enough and most patients were only treated with surgery. The survival rate for breast cancer in those days were not very good and we only understood why when the discovery of the different personalities and behaviour of breast cancer cells were discovered.

Think of cancer in your breast as the "mothership". The headquarters where the trouble started. An operation and radiation treatment are excellent for wiping out the headquarters and taking out the "mothership". The trouble is, breast cancer cells seems to like to travel. So, while the headquarters sits in the breast, some of the cells may "jump off" like little tourists and go to explore other parts of the body via the lymph system. They may not be visible on early scans or blood tests and are quite good at hiding in other parts of the body like the liver, lungs, and bones. If they like it there and nobody notices them, they may decide one day to build a new headquarters – and develop into a tumor elsewhere in the body.

That is what happens when **breast cancer spreads (metastasize)** and become very difficult to deal with. This is where chemotherapy and endocrine therapy (hormone blockers for hormone-sensitive cancers) play a crucial role. These drugs can travel throughout the whole body and destroy any of these cells that may have traveled away from the breast. This way, the chances of them surviving and forming a new cancer elsewhere are greatly limited.

It is this discovery that has made breast cancer survival so excellent. This is also why treating cancer with chemotherapy before surgery is so important with certain types of breast cancers – for those with the more aggressive personalities we don't want those tourists to stand a chance anywhere else in the body and we want to try and make the headquarters in the breast as small and weak as possible.

#### Try to think of your treatment as two separate attacks:

- 1. Take out the mothership (surgery and radiation)
- 2. Kill the tourists and weaken the mothership (chemotherapy and hormone blockers)

#### MEDICAL INFORMATION





The medical team looking after your treatment consists of a team of specialists from the Departments of **Surgery, Radiology, Pathology, Radiation Oncology, Genetics, and Plastic Surgery.** You may also meet a dedicated Breast Cancer Nurse or patient navigator and a Social Worker. The team works together to provide you with the best treatment plan with the best possible outcomes.

#### **TERMS FOR YOU TO UNDERSTAND:**

**Mastectomy:** Surgical removal of the entire breast.

**Lumpectomy:** Surgical removal of the tumor and a small margin of surrounding healthy tissue, also known as breast-conserving surgery.

**Reconstruction:** Breast reconstruction surgery may follow mastectomy to rebuild the breast shape using implants or the patient's tissue.

**Adjuvant Therapy:** Additional cancer treatment after surgery to reduce the risk of cancer coming back.

**Neoadjuvant Therapy:** Treatment before surgery to shrink tumors and make them easier to remove.



Pathology Report: A document containing detailed information about the characteristics of the removed tissue, including tumor size, grade, and the presence of hormone receptors. Preoperative: Activities and interventions that occur before surgery, including assessments, preparations, and discussions with the surgical team. Postoperative: Activities and care provided after surgery to promote healing.

**Recovery Room:** The area where patients are monitored and cared for immediately after surgery until they recover from anesthesia.

**Biopsy:** The removal of a small piece of tissue for examination under a microscope to diagnose or determine the nature of a disease.

Hormone Therapy: Treatment that blocks or interferes with hormones to slow or stop the growth of hormonesensitive tumors.

**Oncologist:** A medical professional who specializes in the treatment of cancer, including surgical, medical, and radiation oncologists.

**General Anesthesia:** A state of controlled unconsciousness induced by medications during surgery.



#### SURGERY ON THE BREAST

After being assessed at the combined clinic, your doctors will recommend one of two procedures on the breast.

#### **BREAST OPTION 1 - MASTECTOMY**

- · Removes the whole breast, including the nipple and surrounding area.
- Muscles supporting the breast stay.
- A drain is always used after the operation to remove extra blood/fluid.
- Sometimes a reconstruction is performed with a mastectomy with either implants or a patient's tissue (Goldilocks Mastectomy or Flap)
- In very select cases, especially when reconstruction is an option, the skin and nipple of the breast may be spared if it is safe.

#### **BREAST OPTION 2 - LUMPECTOMY**

- Takes out the cancer lump & a bit of normal tissue around (1-2 cm).
- Often no drain is needed but this may vary from patient to patient.
- The pathologist will analyze the lumpectomy to make sure all the cancer is removed.
- Sometimes, 1 in 8 people might need another operation if the cancer is too close to the edge of the first one.
- ALL patients undergoing a lumpectomy will require radiotherapy afterward to make sure we limit the risk of the cancer re-occuring.

#### WHEN WILL MY SURGERY TAKE PLACE?

You will be given a letter with a date to meet your surgeon and get ready for surgery. This may not be your admission date in all cases but the day that you are prepped and consented for your operation. Your admission will be confirmed on this date.



Take this letter with you when you are admitted and give it to the **doctor** at the hospital where you are having the operation.



#### Please report to the indicated hospitals at 08h00 in the morning unless being told otherwise



### SURGERY TO THE ARMPIT (AXILLA)

All breast cancer surgeries also involve surgery to the axilla to make sure the lymph nodes have not been affected by the cancer. This is important when making decisions about other treatments you may need. Your doctors will decide on one of two procedures to check or remove your lymph nodes:

#### **1. REMOVING MANY NODES**

AXILLARY NODE CLEARANCE - ANC

- Take out most of the nodes under your arm.
- Done during mastectomy or separately if you're having a lumpectomy.
- About 15-20 nodes are usually removed.
- A drain is left to remove extra blood or fluid.
- This procedure is needed if they have already confirmed before your operation that there may be lymph nodes affected and nipple of the breast may be spared if it is safe.

#### 2. REMOVING SPECIFIC NODES

#### SENTINEL LYMPH NODE BIOPSY - SLNB

- Take out 2 to 3 nodes under your arm connected to where the breast cancer is. Before surgery, you get an injection near the cancer site. A day later, a blue dye may also be injected near the nipple when you are asleep
- These help the surgeon find the specific nodes. The blue dye might be visible on the nipple but usually fades.
- If cancer is found in these nodes, more nodes under the arm may be removed like in axillary node clearance.

#### YOUR HOSPITAL BAG - WHAT TO PACK

- A **clean dressing gown or pajamas** (those with buttons may be easier to put on and take off), personal toiletries, slippers or comfortable shoes;
- Any medicines or inhalers you are taking/using, in their original packaging Something to occupy your time, e.g. book or newspaper
- A bra or a comfortable-fitting camisole to wear when you are discharged.
- Bring your **correct contact telephone numbers** and for your next of kin.

#### WHAT ARE LYMPH NODES?

Lymph nodes are like small filters in your body that clear it from harmful cells. The ones under your arm are important in breast cancer as they may be affected by the cancer cells.

# YOUR HOSPITAL STAY

#### ARRIVE ONE DAY BEFORE

#### **Health Check:**

• Answer health questions, and have vital signs and tests checked.

#### Information Review:

· Confirm details and wear an ID bracelet.

#### Meet the Team:

• Chat with the anesthesia, surgeon, and breast nurse, and sign consent for your procedure.

#### Preparation:

• Follow instructions on when to stop eating and drinking. (Usually at least 6-12 hours before your operation) Diabetic patients may get an IV line, and blood sugar will be monitored.

#### **GETTING READY FOR THEATRE**

- You will put on theatre clothes provided by the nurse.
- You may get a **calming tablet** in the ward.
- Theatre staff will move you on a trolley bed to the theatre.
- The anaesthetist will ask you some questions.
- Vital Sign Monitoring: Blood pressure check, electrodes on the chest for the heartbeat, and a clip on your finger for oxygen levels. You will receive general anaesthetic that will put you to sleep for the duration of the operation.
- **Recovery Room Monitoring:** After surgery, you will be monitored in the recovery room until ready to transfer to a ward.

#### **THE RECOVERY ROOM**

- What will happen as you wake up?
  - Wake up gradually, may feel sleepy and groggy.
  - Nursing staff monitor blood pressure, heart rate, and breathing.
  - Given oxygen if needed.
  - Report any nausea/pain and **don't be scared to ask for medication**.
- Drains and Transfer:
  - You will have **one or two drains** on your chest.
  - You will be moved to the ward when fully awake.

### INFORMED CONSENT:

This is a form you are required to sign to give the team permission. Make sure that you understand what you are signing - and if not, please ask your team for a detailed explanation.

## TAKING CARE OF YOURSELF AFTERWARDS

#### WHAT TO DO RIGHT AFTER SURGERY

- Do deep **breathing exercises** to help chest muscles and blood flow.
- Move your legs if you're in bed to prevent blood clots.

#### **MANAGING PAIN & DISCOMFORT**

- Most patients have minimal pain, but it varies.
- Pain medication will be prescribed; take it when offered to prevent pain from developing.
- Elevate your affected arm on a pillow and start moving as soon as you can.
- Report any unusual pain; it could be an infection or blood clot.
- If you have a drain, it'll be emptied daily, and the fluid measured.
- A **physiotherapist** will advise on exercises to do.

#### AFTER THE OPERATION

- After surgery, you might feel tenderness, soreness, or twinges in the affected area.
- Patients often experience numbness of the skin and upper arm after breast and axillary surgery.
- Don't be discouraged by this as the vast majority of patients will have **little to no side effects in the long-term.**
- Doing your exercises, taking care of your scars, and looking after yourself will minimize your risk of long-term negative symptoms.

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### AVOID COMPLICATIONS BY DOING THESE THINGS:

- Avoid blood pressure, injections, and blood draws on the side where lymph nodes were removed
- Apply insect repellent to avoid insect bites
- Wear gloves when gardening
- Use a cooking mitt when using the oven
- Avoid cutting cuticles, push them back during manicures
- Use an electric razor for shaving under the arm
- Avoid lifting objects greater than 5-10kg
- If a trauma, injury, or break in the skin occurs, wash the area with soap and water and apply antibacterial ointment.
- Eat healthy to support your immune system

## TYPES OF POSSIBLE COMPLICATIONS



#### SEROMA OR HAEMATOMA

#### Haematoma:

- **Blood collection** after mastectomy or breast reconstruction.
- **Causes tightness,** pain, swelling, and bruising.
- The doctor may use a **pressure bandage** or surgical drainage for severe cases.
- Small haematomas may resolve naturally in 4-5 weeks.

#### Seroma:

- Fluid collection under the incision, leads to swelling or discomfort.
- Small seromas often resolve on their own.
- Large or bothersome ones may require aspiration with a small needle which is not painful.

#### SEROMA OR HAEMATOMA

- Expected swelling after the operation.
- **Naturally resolves** as collateral circulation takes over (about a month).
- Not long-term lymphoedema.
- Gentle exercises and arm elevation help (e.g. making a fist and releasing).

#### **LYMPHOEDEMA**

- Results from surgery interrupting normal lymph fluid drainage.
- The rate of lymphedema after ANC is 15% and about 2% after SLNB. See a physio/lymphoedema specialist ASAP once they notice swelling/stiffness in their arm. Early treatment of lymphedema improves outcome.

#### INFECTION

#### **Infection Risk**

• Elevated risk post-operation, particularly for diabetics or those with weakened immune systems.

#### **Symptoms to Watch For**

• **Redness, swelling, fever,** chills, tenderness, or foul-smelling drainage.

#### **Report Immediately**

• Report symptoms quickly for evaluation and possible initiation of a 1-2 week antibiotic course.



# CHEMOTHERAPY

#### WHAT IS CHEMOTHERAPY?

Chemotherapy is a crucial part of cancer treatment, utilizing powerful drugs to combat and control the growth of cancer cells. It aims to shrink tumors, making surgery safer and more effective, especially in cases of breast cancer where immediate surgery may not be feasible.

#### **HOW DOES IT WORK?**

Chemotherapy targets rapidly dividing cancer cells, but it can also affect healthy cells, leading to side effects. Your individual experience with chemotherapy will be unique, and a supportive team of healthcare professionals is here to guide you through the process.

#### **BEFORE STARTING**

Addressing basic health needs and emotional support is crucial before starting chemotherapy. Ensure your mental health is addressed and consider having a family member or friend accompany you during sessions. Various medical tests, such as a heart test (ERNA or ECHO), chest X-ray, CT scan, abdominal sonar, bone scan, and blood tests, may be conducted to assess your readiness for treatment.

#### **EMOTIONAL WELLBEING**

Chemotherapy brings significant changes to your life, impacting your health, daily routines, and relationships. It's normal to experience a range of emotions, and our goal is to support you emotionally throughout this journey.







#### **10 COPING STRATEGIES FOR EVERYDAY LIFE**

#### Focus on Treatment Goals

Keep your treatment goals in mind for motivation on challenging days.

#### Rest and Relax

Prioritize rest, acknowledging reduced energy levels during treatment.



#### **Prioritize Nutrition**

Eating well is crucial for rebuilding tissue and regaining strength.



#### **Exercise When Possible**

Moderate physical activity fights fatigue, boosts appetite, and enhances overall well-being.



#### Explore Hobbies

Try new hobbies or revisit old favorites for mental stimulation. Share coping strategies, connect with fellow patients, exchanging ideas and support in the chemo room.



#### Journaling

Keep a journal to understand your thoughts, activities, and feelings, aiding communication with your healthcare team.



#### Knowledge is Power

Learn about your disease and treatment from reliable resources to reduce fear and increase a sense of control.



#### Ask for help

Learn to ask family and friends to help you with tasks like washing, cooking, and looking after kids. Asking for help and being specific about how people can help you is brave and empowering and allows those who cares for you to show it in a meaningful way.



#### Simplify

Focus on essential tasks, letting go of less important things.



#### BLOOD-RELATED SIDE-EFFECTS

Chemotherapy affects blood cell production, leading to a decrease in red blood cells (RBC), white blood cells (WBC), and platelets. Regular blood tests are conducted before each chemotherapy session to monitor these components.

#### **MONITORING YOUR BLOOD**

Though chemotherapy temporarily decreases blood cell levels, the body can recover and generate new blood cells over time. **Monitoring these levels through blood tests is crucial**, and appropriate interventions, such as transfusions or special injections may be recommended to manage specific conditions.

**RBC (Red Blood Cells):** Carry oxygen; low levels cause *anemia*, resulting in fatigue and breathlessness. Blood transfusions may be necessary.

#### SIGNS OF ANAEMIA

- Tiredness
- Shortness of breath
- Cold and pale hands and feet
- Chest pain



#### WBC (White Blood Cells):

Combat infections; low levels lead to *neutropenia*, making it challenging to resist infections.

#### **PRACTICAL TIPS**

- **1.** Keep a thermometer at home
- Call the clinic if you develop a cough, sore throat, or pain during urination.
- **3.** Wash hands frequently.

**Platelets:** Assist in blood clotting; low levels cause *thrombocytopenia*, leading to bleeding from minor cuts, under the skin, or internal bleeding. **PRACTICAL TIPS** 

- **1.** Use a toothbrush with soft bristles
- 2. When working in the garden, wear protective gloves

#### SIGNS OF NEURTROPENIA

- Fevers and chills
- Cough
- Sore throat
- Skin or mouth ulcers
- Burning urine
- Severe diarrhea
- Bacterial infections are more likely when white cell counts are low, typically 7 - 12 days after chemotherapy.

#### SIGNS OF THROMBOCYTOPENIA

- Easy bruising
- Bleeding from the skin for more than 10 minutes
- Blood in the urine or stools
- Severe headache



#### **NAUSEA & DIET**

Managing nausea during chemotherapy is important for your well-being. If you experience nausea or vomiting, it's crucial to let your doctor or nurse know, as not all chemotherapy drugs have this side effect.

#### CHANGES TO YOUR APPETITE

Chemotherapy may alter your taste and appetite, making you sensitive to strong smells. It's normal not to have much appetite initially, but it improves as you recover.

#### **PRACTICAL TIPS TO COPE WITH NAUSEA:**

- On the day of your treatment, **opt for a light, small meal**.
- **Ginger is an excellent** and natural way to combat nausea while also boosting your immune system you can chew on it or add it to water and tea.
- Eat what appeals to you. Generally, healthy starches like brown rice, brown bread, potatoes, sweet potatoes, veggies, and hot cereals are well-tolerated. Avoid foods that are processed and high in sugar.
- Don't skip meals, as an empty stomach can worsen symptoms. Try nibbling on something you enjoy or drink a healthy shake, smoothie, or soup.
- Stay hydrated by drinking plenty of fluids such as herbal teas, water, sports drinks, and diluted juices. Avoid fizzy and high-sugar drinks.
- **Consider freezing meals** in advance to make eating healthy easier when you don't have the energy to cook or seek help from friends or family.
- Sensitive Smells: Avoid odors, especially during meals, that make you feel sick.
- **Maintain a regular diet** with enough calories to support your strength and immune system.
- Reduce intake of salt, very spicy foods, and dairy products if they worsen nausea.

Acid reflux, when food backs up into your esophagus, may cause burning or pain. If you experience this, inform the chemo Sister for appropriate medication.

#### **COPING WITH ACID REFLUX:**

- Avoid acidic and very spicy food
- Healthy Fats, High Fiber: include fruits, lots of vegetables, whole grains, nuts, and healthy fats like olive or coconut oil, avocados, and fish in your diet. This is also excellent for helping your body heal.
- **Coffee and Alcohol** should be limited as this can worsen reflux

#### DIARRHEA

Certain chemo drugs may cause diarrhea. **If it's severe or exceeds 5 bowel movements in 24 hours**, contact the clinic sister. Over-thecounter meds can help, but get approval from the chemo team first.

#### **CONSTIPATION CONCERNS**

Combat constipation with more **fiber and water. Stay active.** If it persists, inform the chemo sister or doctor for potential solutions. Adding **psyllum husk or slippery elm** may help.

#### ORAL HYGIENE, SKIN & EYES

Chemotherapy can impact the cells lining the mouth and throat, leading to a condition called "stomatitis," causing discomfort and pain while eating and swallowing. Skin Sensitivity occurs and sun exposure may cause dryness, itching, and changes in skin color. Nails can darken, and lines may appear. These changes are temporary and will stop once treatment ends.



Certain chemotherapy drugs can lead to eye issues.

#### **Possible Symptoms:**

- Difficulty with contact lenses, causing irritation.
- Blurry vision and clogged tear ducts.
- Excessive tearing due to chemo.
- Sensitivity to light.

#### TIPS FOR GOOD MOUTH CARE

- Maintain Oral Hygiene: Keep your mouth clean and check for issues like bleeding areas or white patches. Report any changes to prevent mouth infections.
- If at all possible, **visit your dentist as your teeth** may become brittle, more sensitive, and more prone to cavities.
- Watch Your Diet: Avoid very acidic and carbonated drinks, as well as hot and spicy foods that can exacerbate discomfort.
- **Rinse with Bicarbonate of Soda:** After meals, rinse your mouth with a solution of a teaspoon of bicarbonate of soda in a glass of lukewarm water to soothe irritation.
- Keep Your Mouth Moist: Sucking on hard sweets has been reported to provide relief.

#### **CARING FOR SKIN & NAILS**

- Avoid prolonged sun exposure.
- Always use **sunblock** when outdoors.
- Wear a hat when hanging laundry and cover your arms.
- Keep **skin moisturized** with a good moisturizer to prevent dryness. You can also use **castor oil or coconut oil** to hydrate your skin.
- Massage cuticle cream or castor oil into the cuticle area to prevent dryness, splitting, and hangnails.
- Wear gloves while doing chores such as washing the car or the dishes.





#### FATIGUE

Fatigue is a common chemo side effect, ranges from mild to feeling completely drained. Unlike regular tiredness, it doesn't improve with rest but typically lessens once chemo concludes.

#### **Practical Tips:**

- **Prioritize rest** and incorporate short breaks during the day.
- Engage in regular, **gentle exercises**
- Maintain a balanced diet, stay hydrated, and limit activities to conserve energy.
- Seek help from friends, family, or neighbors when needed.
- Rise slowly to prevent dizziness after sitting or lying down.
- **Discuss any sleep issues** with the doctor or chemo sister for tailored advice and support

#### NEUROPATHY

**Symptoms:** Tingling, burning, numbness, or pain may occur due to nerve dysfunction during chemotherapy. Commonly affected areas are fingertips and toes, but other areas can be involved.

Alert Signs: Report any sense of imbalance or difficulty feeling your fingertips to the chemo Sister or Doctor. Early reporting helps control symptoms and prevents further nerve damage.

#### **Practical Tips for Comfort**

- Avoid tight shoes or socks
- Opt for soft, loose cotton socks and padded shoes.
- For burning pain, cool hands or feet in cold (not icy) water for 15 minutes twice a day
- Massage your hands and feet to improve circulation, stimulate nerves.

#### **FERTILITY & SEXUAL HEALTH**

**Birth Control Crucial:** Due to potential toxicity to unborn children and the risk of stimulating hormone-sensitive cancer cells use non-hormone birth control like the copper T during chemotherapy. Changes in menstrual cycles may occur, even leading to the absence of periods. Women should still take precautions not to get pregnant even in the absence of a period.

**Menopause Possibility:** Chemotherapy may temporarily halt periods or induce permanent menopause. Effects vary based on chemotherapy type, age, and proximity to natural menopause.

**Menopausal Symptoms:** Hot flushes, decreased sexual drive, vaginal dryness, mood changes, and sleep disturbances may occur. Don't hesitate to discuss symptoms with the chemo Sister or doctor.

#### What to Do:

- **Dietary Choices:** Eat naturally cooling food like watermelon and cucumber and drink cold water.
- Prescription Medication: The doctor may recommend medication.
- Avoid over-the-counter "natural" anti-menopause medication especially if you have hormone-sensitive cancer as these still contain estrogen that may stimulate the growth of cancer cells.
- **Comfortable Clothing:** Wear light daytime clothing and cotton pajamas for better sleep.
- Buy a hand fan these are very handy to cool you down and add flair to any outfit.
- **Vaginal Health:** Use vaginal creams regularly for irritation. Consider vitamin E or olive oil for increased lubrication during sexual activity.

#### **HAIR LOSS**

For many, losing hair (alopecia) is a challenging aspect of chemotherapy. Not all chemo drugs cause hair loss, so consult with the chemo sister or doctor to understand what to expect.

Hair loss typically begins 2-3 weeks after starting chemotherapy. The extent varies -from minimal loss to complete loss of head, eyelash, eyebrow, and body hair. Hair loss is usually temporary and grows back after treatment. Although it can't be prevented, it doesn't affect everyone.

New hair growth usually occurs 2-3 months after stopping

**chemotherapy,** with potential differences in color and texture. I may initially be soft and curly, returning to its original texture over time.

#### **COPING WITH HAIR LOSS**

Coping strategies can help navigate the emotional and practical aspects of hair loss.

- Before hair loss starts, you may opt to cut your hair or shave your head.
- Use a soft pillowcase or place a soft towel on the pillow to ease cleanup during shedding
- **Consider a soft satin pillow** to minimize distress from seeing hair on the pillow.
- Purchase a drain catch for the shower to collect shedding hair.
  - Choose headwear that makes you comfortable whether it's a wig, hairpiece, scarf, hat, or turban. Protect your scalp from sunlight and cover up outdoors.





#### **CHEMO BRAIN**

**The Facts:** Research indicates that chemo can impact thinking for up to 10 years post-treatment. It subtly affects concentration, memory, understanding, and reasoning.

#### **Identifying Chemo Brain:**

- Forgetting usual things (memory lapse).
- Trouble concentrating, short attention span, occasional "spacing out."
- Difficulty remembering details, names, dates, or significant events.
- Struggling with multitasking, slower task completion, disorganization.
- Trouble recalling common words to complete sentences.

#### MANAGEMENT TIPS:

- Stay Organized: Use a detailed daily planner for reminders.
- Brain Exercise: Engage in word puzzles to stimulate your mind.
- Prioritize Rest: Ensure enough sleep and rest.
- Physical Exercise: Regular exercise enhances alertness and mood.
- **Vegetables in Diet:** Studies link increased vegetable consumption to brain alertness.
- Establish Routines: Stick to consistent daily routines.
- Single Task Focus: Avoid multitasking; focus on one thing at a time.
- Seek Support: Don't hesitate to ask for help; loved ones can assist with tasks.
- Mindset Matters: Laugh about uncontrollable situations to cope better.
- **Consider using omega 3 and 6 fatty acids** as supplements or increase food that naturally contains these like nuts and fish. You can also try Biostrath as a mind-boosting supplement.



#### WHAT IS RADIATION THERAPY?

Radiation therapy is treatment with high-energy rays (or particles) that destroy cancer cells. Some women with breast cancer will need radiation, in addition to other treatments. Radiation therapy is used in several situations:prevents further nerve damage.

- After a lumpectomy (removal of the tumor), to help lower the chance that the cancer will come back in the same breast or nearby lymph nodes.
- After mastectomy in certain cases (if the cancer was larger than 5 cm, if cancer is found in many lymph nodes, or if certain surgical margins have cancer such as the skin or muscle.
- If cancer has spread to other parts of the body, such as the bones or brain.

#### TIMING OF THE TREATMENT

If you will need external radiation therapy after surgery, it is usually not started until your surgery wound has healed, which often takes a month or longer. If you are getting chemotherapy as well, radiation treatments are usually delayed until chemotherapy is complete.

The main type of radiation therapy that we use to treat breast cancer is external beam radiation therapy (EBRT). A machine outside the body focuses the radiation on the area affected by the cancer.

#### WHERE WILL IT BE FOCUSED?

This will carefully be determined and planned by your radiation oncology team and will depend on many factors. Before your radiation starts, you will be given an appointment for a special CT scan called a planning scan.

- If you had a mastectomy and no lymph nodes had cancer cells but the cancer was very big or the margins are close, radiation is focused on the chest wall, the mastectomy scar, and the places where any drains exited the body after surgery.
- If you had a lumpectomy, you will most likely have radiation to the entire breast (called whole breast radiation), and an extra boost of radiation to the area in the breast where the cancer was removed (called the tumor bed) to help prevent it from coming back in that area.
- If cancer was found in the lymph nodes in the armpit (axillary lymph nodes), this area may be given radiation. The area treated might also include the nodes above the collarbone (supraclavicular lymph nodes) and the nodes beneath the breast bone in the center of the chest (internal mammary lymph nodes).

#### HOW TO PREPARE FOR TREATMENT

Before your treatment starts, the radiation team will carefully figure out the correct **angles for aiming the radiation beams and the proper dose of radiation**. They will make some ink marks or small tattoos on your skin to focus the radiation on the right area. **External radiation therapy is much like getting an X-ray,** but the radiation is stronger. **The procedure itself is painless.** Each treatment lasts only a few minutes, but the setup time—getting you into place for treatment—usually takes longer. **The whole process should not take longer than 15-20 minutes.** 

#### **DURATION OF TREATMENT**

This may vary from patient to patient and from hospital to hospital. It also depends on whether you will receive whole breast radiation, accelerated partial breast radiation, chest wall radiation, or lymph node radiation. **On average, most patients will be offered radiation therapy every day of the week (Monday-Friday) between 3-6 weeks.** In the case of accelerated partial radiation, only one week of radiation will be done.

#### **POSSIBLE SIDE-EFFECTS OF BEAM RADIATION**

Unlike chemotherapy, most of the side effects is LOCAL to the skin of the breast. This is usually temporary and recovers fairly quickly once the treatment is stopped. Most skin changes get better within a few months.

#### YOU MAY EXPERIENCE:

- Swelling and tenderness in the breast/ chest wall/ armpit
- **Skin changes** in the treated area similar to a sunburn (redness, skin peeling, darkening of the skin)
- Some women may find that radiation therapy causes the **breast to become** smaller and firmer.
- Radiation may **affect your options for breast reconstruction** later on. It can also raise the risk of problems with appearance and healing if it's given after reconstruction.
- Women who have had breast radiation may have problems breastfeeding.
- Radiation to the breast can sometimes **damage some of the nerves in the arm**. This is called brachial plexopathy and can lead to numbness, pain, and weakness in the shoulder, arm, and hand but this is quite rare.
- Radiation to the underarm lymph nodes might cause lymphoedema (as with the removal of the lymph nodes) but this is usually rare or minimal.
- Radiation therapy may weaken the ribs, which could lead to a fracture but this is very rare
- In the past, parts of the lungs and heart were more likely to get some radiation, which could lead to long-term damage of these organs in some women. Modern radiation therapy equipment better focuses the radiation beams, so these problems are rare today.
- A very rare complication of radiation to the breast is the development of another cancer called angiosarcoma

#### HOW TO MANAGE AND MINIMIZE SIDE-EFFECTS

#### Taking care of your skin.

- At the beginning of treatment, before you have any side effects, **moisturize the skin after your daily treatment with an ointment** such Eucerin, Aquaphor, or Radiacare. You can also use coconut oil and Aquas Cream
- Make sure to follow the instructions given to you by your oncology team carefully.
- AVOID any sun exposure to the area, it is best to stay out of direct sunlight all together while getting your radiation therapy
- AVOID applying any ointments or creams to the skin that are not approved by your team as this may cause further harm
- Wear loose-fitting shirts, preferably cotton.
- When showering: **Use warm** rather than hot water and try to not let shower water fall directly on your breast. Avoid harsh soaps and soaps with fragrances.
- Regularly dust the breast area and inside skin folds with corn starch (Maizena) to absorb moisture, reduce friction, and keep you smelling fresh. Apply it with a clean makeup brush or put some cornstarch into a single knee-high nylon or thin sock knot it at the top and pat gently over the area.
- With or without radiation, **yeast infections** are common in the skin fold under each breast —particularly during warm weather in women with large breasts. Signs of yeast infections are redness, itchiness, and sometimes a faint white substance on the skin. If you have a yeast infection, take care of it before radiation starts and notify your doctor. An anti-fungal cream (such as athlete's foot medicine) usually works well.
- For **mild pinkness, itching, and burning during treatment**, apply an aloe vera gel. You can also use 1% hydrocortisone cream (available without a prescription at any drugstore). Spread the cream thinly over the affected area 3 times a day.
- If your symptoms worsen ask your **doctor for a stronger steroid cream** available by prescription. Some people get some **relief by blowing air on the area** with a hair dryer setting on "cool" or "air" (no heat) or standing in front of a fan.
- If your skin becomes dry and flaky during the course of your treatment, moisturize frequently with fragrance-free moisturizer or something natural like coconut oil and cleanse skin gently. If your skin forms a blister or peels in a wet way, leave the top of the blister alone! The bubble keeps the area clean while the new skin grows back underneath. If the blister opens, the exposed raw area can be painful and weepy. Keep the area relatively dry and wash it with warm water only. Patch the area dry and then apply a NON-STICKY dressing apply coconut oil or petroleum jelly before putting anything against the skin and notify your doctor.
- If the pain is very severe, take a **painkiller like paracetamol and Brufen**.
- AVOID swimming and chlorine.
- After treatment make sure to always **wear sunblock** and keep up caring for your skin to achieve optimal healing.

#### **MEDICAL INFORMATION | ENDOCRINE THERAPY**

# ENDOCRINE THERAPY

#### **ENDOCRINE THERAPY (HORMONE BLOCKERS)**

Some types of **breast cancers are sensitive to the female hormones oestrogen and progesterone** as we explained in the "Different types of Breast Cancer" section. The breast cancer cells have receptors (proteins) that attach to oestrogen and progesterone, which help them grow. Treatments that stop these hormones from attaching to the cancer receptors or lowering the oestrogen levels so much that they can't attach, are called hormone blocking or endocrine therapy and are a very important part of the treatment of these cancers.

**You can think of the hormones as "food" for cancers** and by taking away the food with the hormone blockers, we are starving the cancer cells and therefore stopping its growth. Hormone blockers can reach cancer cells almost anywhere in the body and not just in the breast which is what makes it so powerful in helping to treat the cancer and preventing it from coming back or spreading.

#### WHEN IS ENDOCRINE THERAPY USED?

Hormone blockers are often used both before and after surgery to help reduce the risk of the cancer coming back. Patients are encouraged to use **these tablets** every day for at least 5 years when the risk for recurrence or spread is the highest. Hormone blockers can also be used to treat cancer that has come back after treatment or that has spread to other parts of the body.

#### **TWO TYPES OF ENDOCRINE THERAPIES:**

#### **#1 TABLETS THAT BLOCK** THE OESTROGEN RECEPTORS

- Tamoxifne
- Fulvestrant (Faslodex)

These tablets are usually **prescribed to younger patients that are not in menopause (still getting peroids)** yet and have higher levels of circulating oestrogen. By blocking the receptors we can starve the cancer cells even though there is oestrogen circulating in the body. Occasionally we need to try and suppress the ovaries to make less oestrogen (with an injection or by removing them) in order to make these tablets work even better in women with very high oestrogen levels.

#### #2 TABLETS THAT LOWER OESTROGEN LEVELS

Aromatase Inhibitors
(AI) like Arimidex

These tablets are **usually prescribed** to patients who are already in menopause (stopped getting peroids). We still need to lower the levels of estrogen because oestrogen is not only produced in the ovaries but also elsewhere in the body like fat cells.

#### **MEDICAL INFORMATION | ENDOCRINE THERAPY**

#### WHAT ARE THE SIDE-EFFECTS?

The side-effects are very similar to the symptoms that women experience when going through menopause and can vary from patient to patient. Some patients (especially those already in menopause) experience very little to no side effects and for others the adjustment can be quiet challenging. All these side effects are manageable and should not prevent you from taking this very important part of your treatment.



COMMON SIDE-EFFECT FOR TAMOXIFEN	COMMONE SIDE-EFFECTS FOR AROMATASE INHIBITORS
Hot flushes	Arthralgia (muscle aches and pains) Joint pain
Vaginal dryness	Osteoporosis
Low sex-drive	Weight gain
Dyspareunia (pain during sex)	Headache
Tiredness	Low sex drive
Mood changes	Tiredness
Weight gain	Insomnia(difficulty to sleep)
	Mood changes
	Hypercholesterolemia (high cholesterol)

#### **ARE THERE RISKS IN TAKING ENDOCRINE THERAPY?**

Tablets that lower the level of oestrogen (aromatase inhibitors) have very little risk except for osteoporosis (thinning of the bones) for which you will be prescribed calcium and vitamin D tablets to help keep your bones strong. **Tablets that blocks the oestrogen (Tamoxifen) have some risk but these occur rarely, but could increase risk of:** 

- Endometrial hyperplasia (thickening of the wall of the womb) visit your gynae clinic once a year and report any abnormal vaginal bleeding
- **Polyp (growths) in the womb.** Visit your gynae clinic once a year and report any abnormal vaginal bleeding.
- Endometrial (womb) cancer (rare). Visit your gynae clinic once a year and report any abnormal vaginal bleeding or lower abdominal pain.
- **Deep venous thrombosis (blood clot in leg)**. If you experience sudden sharp and severe pain in your lower leg (calve muscle), report to your nearest emergency unit immediately.
- **Pulmonary thromboembolism (blood clot in lungs)**. If you experience sudden shortness of breath, report to your nearest emergency unit immediately.

#### **MEDICAL INFORMATION | ENDOCRINE THERAPY**



#### WHAT CAN I DO TO LIMIT BY SIDE-EFFECTS?

Don't despair and don't give up. Most importantly, **do not stop your treatment**, but rather discuss it with your doctor.

There are several things that you can do to take control of your symptoms and overall well-being (also see our section on Deliberate Living at the end of the book as many of these principles will aid you greatly in managing your symptoms).

- EXERCISE has been shown in many studies to improve joint and muscle aches, increase energy levels and improve mood. You don't have to run a marathon but regular brisk walks, stretching and some simple strength exercises will make a big difference.
- SLEEP will improve your mood, energy levels and ability to cope with sideeffects
- EATING a diet rich in fibre, healthy grains and good fats will help manage your weight, joint health and mood
- **COOL** yourself by using a fan, wearing light clothing and drinking plenty of water. You can also use cold compresses like an ice pack) on your wrists, feet and around your neck as cooling these points have a cooling effect on the body
- AVOID any "natural" menopause medication as these still contain oestrogen (even if it comes from plants) that is bad for your cancer
- **MEDICATION** that your doctor can prescribe to help you manage your side effects include:
  - Venlor/Venlafaxine (an anti-depressant that can help with hot flushes and a low mood
  - Clonidine (that can help with hot flushes)
  - An anti-inflammatory that can help with joint pain
  - Amitriptyline that can help with sleep, mood and pain
  - Supplements like vitamin D, vitamin E, Omega 3 and 6, Calcium and magnesium that can help with your bone strength as well as muscle aches and pains
- **STAY POSITIVE** as a positive mindset is the most powerful tool in the world to not only survive but thrive!
- **SHARE** your challenges with fellow patients, friends, or family, and don't ever be ashamed to ask for help.



### Some patents may be referred for genetic testing if your treatment team feels that this will benefit you and your family.

#### Patients that will typically be referred include:

- Young patients diagnosed before the age of 50 with breast cancer
- Patients with a very strong family history of breast cancer, especially if it includes a first degree relative like a mother or sister
- Any male patient diagnosed with breast cancer
- A patient with a very strong family history of other cancers like colon cancer A patient with cancer in both breast

#### WHAT IS GENETIC COUNSELLING & TESTING?

A genetic counselling session starts with gathering information regarding a patient's personal and family history of cancer. Based on this information, the diagnosis or risk of having a certain genetic cause for the cancer is discussed. The genetic counsellor may also explain how this gene may be passed on in a family and how it may impact possible other conditions. If appropriate and the patient agrees, a simple blood test will be taken to test for certain genes that are associated with the development of breast cancer. The most common of these genes are the BRCA1 and BRCA2 genes. Other genes may be tested for if there is a strong family history of other cancers.

#### WHY MAY GENETIC TESTING BE IMPORTANT?

### If a genetic reason for your breast cancer is found it may impact on the following:

- The type of surgery you have it may be better to consider rather having both breasts removed to limit your future risks
- It will enable your team to better monitor you for other cancers or diseases that may be associated with such a gene and refer you to other doctors that may help with this like a gynaecologist (the breast cancer gene may also cause cancer of the ovaries)
- It will help your family if you have children they may also want to test for the gene and be more proactive in screening and follow-up to try and prevent a cancer diagnosis

Genetic testing may sound scary but it can be very empowering to take control of your health and future. If you are offered genetic testing, please consider taking the opportunity for both yourself and your loved ones. **KNOW YOUR HOSPITAL** 



DATE	TIME	PLACE	REASON	TO BRING/REMEMBER



#### **ABOUT PROJECT FLAMINGO**

At Project Flamingo, we believe that every cancer patient deserves access to timely treatment and heartfelt support, no matter their circumstances. We put this belief into action by helping where our skills and experience are most needed: in the public healthcare system in South Africa. Since 2010, we have made a tangible impact on thousands of patients' lives by providing **timely surgeries and compassionate, holistic patient support** to assist them at the most vulnerable stages of this disease.

Contact us - info@projectflamingo.co.za







We understand that when you are at the hospital, you may feel overwhelmed by information and don't always know what questions to ask your doctor or healthcare team.

#### WRITE DOWN YOUR QUESTIONS

Use this page to write down questions you would like them to answer or things you need better explained at your next appointment. Your family or friends may be able to help you with important questions to ask.






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# SUPPORTING MOMENTS OF CARE



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