Due to the Oncology Crisis in Gauteng Public Hospitals, Is There Any Hope Left for Inflammatory Breast Cancer Patients in South Africa?

Inflammatory Breast Cancer (IBC) is certainly breast cancer. In fact, it's a breast cancer overachiever. It is extremely rare, incredibly volatile and has a competitive spirit that makes it extremely difficult to beat. And it really loves being ignored, which is exactly what the Gauteng Department of Health in South Africa is currently doing.

In this article we will follow the path of Jennifer Blowers, one of the unfortunate few required to battle and survive IBC in South Africa. We'll learn how this disease is affecting her life and how the current Gauteng oncology crisis, combined with certain obstructive breast cancer policies, protocols and guidelines, is making her already-immense struggle against this cancer beast even more challenging and demanding to win.

Bear in mind while you read this that it could be your mother, sister or daughter, a close friend or, God forbid, it could even be you.

> *Inflammatory breast cancer (IBC) accounts for 0,5 to 2% of invasive breast cancers but contributes to 7% of breast cancer mortality. The median overall survival among women is less than four years, even with multi-modality treatment options.*
>
> — **Dr. Daleen Geldenhuys** in **Buddies For Life Magazine**

Introduction

Jennifer Blowers is feeling let down.

Jennifer was diagnosed with a rare form of breast cancer in February 2021. According to the **National Cancer Institute of the United States**, **Inflammatory Breast Cancer (IBC)** affects 1-5 percent of all breast cancers diagnosed in that country, and percentages are similar the world over.

IBC is an aggressive form of breast cancer. Tumours appear and grow at alarming rates compared to those of other breast cancers. This means that IBC patients are, according to the **TNM system**, immediately diagnosed as **Stage III**. Stage III means that cancer has already spread to the tissue or lymph nodes close to the affected breast.

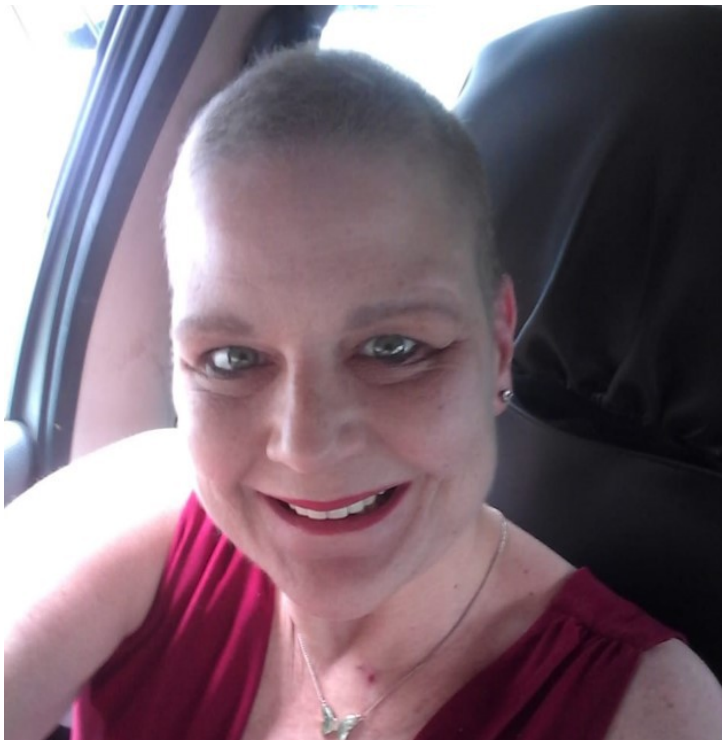
IBC Diagnosis

Jennifer Blowers visited the government-run **Helen Joseph Hospital** after noticing a mass in her right breast. As she had recently started to go to gym, she thought the mass was exercise-related but then realised it had grown significantly over the space of a week. An examination, followed by scans and a biopsy, confirmed Jennifer's fear. She had breast cancer. But even worse news was to come.

A consultation with **Professor Carol Benn**, Head of the **Helen Joseph Breast Care Clinic** and a world-renowned surgeon specialising in breast disease, followed. She confirmed that Jennifer had IBC. Benn confirmed that Jennifer's tumour was **HER2-Positive**. Despite being faster growing than its HER2-Negative counterpart, this meant that

oncologists could make use of a form of chemotherapy called **Trastuzumab**. The drug would target the tumour cells directly, shrinking the tumour to an operable size for Professor Benn to remove later.

Jennifer's chemotherapy was scheduled to start in April 2021 at **Charlotte Maxeke Johannesburg Academic Hospital (CMJAH)**, another government facility.



Jennifer Blowers during 2021

Delays in Chemotherapy

As luck would have it, a week before Jennifer's chemotherapy appointment **CMJAH experienced a devastating fire**. The hospital had to close its doors, delaying the start of Jennifer's treatment. Her appointment was subsequently moved to the **Chris Hani Baragwanath Academic Hospital (CHBAH)**. Pandemonium greeted Jennifer **on arrival for her chemotherapy** at CHBAH in May 2021, after a delay of 3 weeks. The influx of patients to the temporary oncology unit caused chaos among staff and disorganisation in treatment protocols.

Needless to say, Jennifer didn't start her chemotherapy that day. She returned to CHBAH a week later and finally began the treatment. Despite requesting the Trastuzumab, the drug was not prescribed. According to the on-site oncologists, it did

not form part of the **National Department of Health's Breast Cancer Policy** protocols. They told Jennifer that the administering of Trastuzumab would be possible later in the process.

Trastuzumab Shock

Jennifer would find out much later that, in her case, the government would not initially cover the cost of Trastuzumab. Before surgery it was only covered for Stage I and II breast cancer patients as their outcomes were "*more positive*". Depending on the success of any surgery, she could qualify for 6 months of Trastuzumab treatment afterwards.

This highlighted the fact that exactly the same treatment protocols applicable to less volatile breast cancers also applied to IBC. Despite a more aggressive and rapid growth, and an "entry level" Stage III classification, the lifesaving drug needed to stem and reverse Jennifer's tumour growth was excluded from the treatment protocol.

IBC falls under the National Department of Health's **Clinical Guidelines for Breast Cancer Control**. In this document there is no differentiation made between IBC and other forms of Stage III breast cancer. In fact IBC is hardly mentioned in either the guidelines or policy documentation at all. The internationally-accepted acronym for Inflammatory Breast Cancer doesn't even warrant a mention.

FNAC	Fine needle aspiration cytology
H&E	Haematoxylin and eosin
HER-2	Human epidermal growth factor receptor 2
HERA	Herceptin Adjuvant
HR	Hazard ratio
IDC	Invasive ductal carcinoma
IHC	Immunohistochemistry
ILC	Invasive lobular carcinoma
LABC	Locally advanced breast cancer
LCIS	Lobular carcinoma in situ
LHRH	Luteinizing-hormone-releasing hormone
LN	Lobular neoplasia
LTR	Lifetime risk
MDT	Multi-disciplinary team

An excerpt from the Acronym section of one of the official NDoH documents

As IBC can never be classified as Stage I or II breast cancer, Jennifer stood no chance of receiving government-funded Trastuzumab before surgery. Without Trastuzumab though, the likelihood of Jennifer even having surgery was minimal. Professor Benn had already told her that any surgery depended on Trastuzumab targeting and shrinking her tumour. It was already clear that standard chemotherapy was not going to do this.

A Dire Prognosis

After 2 treatments at CHBAH, Jennifer was relocated back to CMJAH for the rest of her chemotherapy. After her first treatment there, Jennifer asked her new oncologist, **Dr. Yusuf Mayet**, for a prognosis. Mayet informed her that her prognosis without Trastuzumab was very poor. He suggested that Jennifer buy the drug privately as the government would not supply her with it. Jennifer's tumour was still growing despite the chemotherapy!

Jennifer immediately sought a second opinion from **Dr. Georgia Demetriou**, the head of the **Department of Medical Oncology** at CMJAH. Demetriou confirmed Dr. Mayet's prognosis, immediately prescribing Trastuzumab and telling Jennifer to buy it herself if she could. CMJAH would then administer it for her. Before meeting with Dr. Mayet, Jennifer had not been given any option to buy Trastuzumab herself by any oncologist. She was also never informed of its urgency before requesting the prognosis.

Hope At Last?

Jennifer scraped together funds, borrowing from her family, to buy her first 2 vials of Trastuzumab. Her sister in the UK started a **gofund.me fundraiser** to help with the costs. Within days CMJAH administered the first of many privately-secured Trastuzumab treatments for Jennifer. The drug had an immediate impact and the tumour began shrinking fast.

If the option of buying Trastuzumab had been offered sooner, it would have accelerated Jennifer's recovery. The tumour would have started to shrink instead of growing larger. As a result, Jennifer could have undergone surgery much earlier than she did.

Surgery and Adjunctive Therapy

As it transpired, Jennifer underwent a **double mastectomy** operation in December 2021. Some of her lymph nodes were also removed and the operation at Helen Joseph Hospital was deemed a success. Professor Benn, who carried out the operation on her day off, referred Jennifer back to Dr. Mayet at CMJAH. Both her surgeon and oncologist stressed that Jennifer should organise radiation treatment urgently. Receiving radiation within 2 to 3 months of the operation would restrict the chance of any cancer recurrence.

Standard 4.10: All patients suitable for surgery or adjuvant radiation referred for treatment within 42 days of referral following MDT decisions

Workup procedure must be completed by the referring institution. Refer to National Policy Framework and Strategy on Palliative Care.

Standard 4.11: Radiation should be offered to all patients after breast conserving surgery within 90 days

Workup preparation must be completed at the treating institution.

Standard 4.12: Post-mastectomy radiation should be offered in high-burden of disease within 60 days

An excerpt from the National Department of Health's "Clinical Guidelines for Breast Cancer Control and Management" document

Dr. Mayet has since scheduled Jennifer for 6 months of government-funded Trastuzumab treatment. Thereafter, she will need to cover any costs of the drug herself once more. Jennifer will need ongoing Trastuzumab treatment to keep any cancer at bay whilst awaiting radiation.

Now back to why Jennifer still feels let down…

Radiation Treatment Delays

Jennifer managed to book her radiation assessment for February 2022, already 2 months after her surgery. As the radiation crisis at CMJAH is well publicised, she had already secured the required scans before the assessment or the process would have been delayed further. The assessment, carried out at the **Radiation Oncology Department** at CMJAH, resulted in the radiologist telling Jennifer that she would need daily radiation for a 3 week period. After further investigation, this is the very least that should be administered. The radiologist informed her that someone would make contact with a treatment date.

Before her next Trastuzumab treatment Jennifer reported back to Dr. Mayet with this information. Mayet was insistent that she keep pushing the radiology department as radiation was essential within 3 months of her operation. Any further delays would likely severely hamper its effectiveness. This was even more important in Jennifer's case as IBC has a **high risk of recurrence** compared with most breast cancers.

Jennifer immediately returned to the CMJAH Radiation Oncology Department. She consulted with another radiologist who told her that Dr. Mayet's information was not correct and that she would be quite safe during any delays. He told her that even receiving radiation 18 months after surgery would be fine as Jennifer could be placed on a 5 year course of **Tamoxifen**, a hormone therapy drug, instead. He also told Jennifer that he would put her file on his boss's desk for urgent attention.

Further investigation has established that Tamoxifen would, in fact, be useless in Jennifer's case. Her **hormone receptor-negative cancer** means that hormone therapy drugs would be of no use whatsoever. Did this radiologist even read Jennifer's file before putting it on the desk?

Fighting for Treatment

It is now May 2022 and there remains no date set for Jennifer's radiation treatment to begin. In early April, in response to her plea for help, Jennifer received feedback via one of the Helen Joseph Breast Clinic's navigators. The navigator had spoken to a senior radiation oncologist from the CMJAH Radiation Oncology Department. The radiation oncologist told her that they had escalated Jennifer's radiation treatment but that it wouldn't happen in the next day or two, or even next month. She estimated it would happen in about **6 months**!

The radiation oncologist gave some reasons for the delay. She said there were many others requiring urgent radiation, including palliative care patients.

> *Palliative care is care for the terminally ill and their families, especially that provided by an organised health service.*
>
> — Oxford Dictionaries

Palliative care is an important part of the public healthcare system, but does it trump saving a life, thereby preventing yet another potential palliative care patient?

All of This… and Bipolar Mood Disorder

As if Inflammatory Breast Cancer isn't enough, Jennifer also lives with Bipolar Mood Disorder. For years she has worked to control this affliction through a disciplined adherence to her treatment plan. Jennifer has visited a psychologist every fortnight for over a decade and her dedication to self-improvement has resulted in her earning an **honours degree in Psychology** through **UNISA**. Jennifer's continued ability to control her condition is now being tested by her struggle with cancer. While she has succeeded admirably so far, the constant doubts and delays make this control more difficult to maintain.

Every month for years Jennifer has collected her bipolar medication from Helen Joseph Hospital. There she is able to join a dedicated pharmacy queue designed to minimise stress levels. Throughout her cancer treatment, CMJAH has offered no consideration of Jennifer's condition despite her declaration of the same in every hospital document she has filled out.

A Meeting with CMJAH Radiation Oncology

With help from the **Cancer Alliance**, Jennifer secured an April meeting with CMJAH Radiation Oncology senior management. Management blamed cancer radiation treatment delays on the hospital's lack of human and equipment resources, which revealed nothing new. They pointed out that solving these issues lay with the **Gauteng Department of Health** so, in effect, their hands are tied. A couple of Radiology Oncology members do make up part of a newly-formed Cancer Task Team however.

According to those in attendance at the meeting, between 300 and 400 breast cancer patients currently await radiation, and planning each patient's treatment takes 3 to 5 days to complete. *"A few months"* ago the department created an expedited list for urgent cases which presently includes 56 patients.

CMJAH granted no concessions to Jennifer during the meeting. They did tell her that her case has "*been expedited"* but refused her request to be added to the 56 patient expedited list. Instead, her name would go onto the next list, which they would only compile once the radiation planning of those on the current list was almost complete. Not basing a case on urgency but rather on the case's age alone seems to reveal an inflexibility in the radiation triage process.

Department management continually made reference to how long certain patients had been waiting for radiation. Is this because other patients deemed "more urgent" had been moved ahead of them in the queue? Or is it because the "expedited list" was only created "*a few months"* ago?

After the meeting's conclusion, a senior radiology oncologist who had been present told Jennifer privately that her case would not take preference to that of "*a gogo from Soweto"*. Jennifer was taken aback by this comment. At no stage has she ever wanted to jump the queue because of any assumed "privilege", and had already expressed concern for other patients during the meeting. All that Jennifer expects, as all patients should, is to be correctly triaged according to the seriousness of her diagnosed condition.

The same oncologist then gave her an appointment for **a check-up in 3 month's time**. As stated in the meeting, the Radiation Oncology department does like to "*keep a close eye"* on their patients.

Further Questions for the Radiation Oncology Department

A few days after the meeting, in response to an offer to deal with "*any issues"* Jennifer might still have, some pertinent questions were emailed to CMJAH's head of Radiation Oncology, **Dr. Duvern Ramiah** . Nearly 3 weeks have passed without a response.

Certain of the questions posed directly were:-

- You mentioned that an expedited list for triage purposes has been compiled over the last couple of months. Please give me some clarification

as to why this list was not employed sooner given that delays have been over a much longer period?

- Does the 56 patient list include breast cancer patients only?
- Why are patients not being added to the list as they are assessed? Surely there may be newer urgent cases that should be incorporated as they are found, possibly deserving higher triage status than some already on the list?
- Are all newer cases having to wait until the planning of patients on that list is complete before being added to a new expedited list? The impression given is that new cases will not be added to the existing expedited list.
- How many Inflammatory Breast Cancer patients are being treated or awaiting radiation? How many of these IBC patients are on the expedited list of 56?
- How long have the IBC patients (if any) been waiting for radiation?
- Are these IBC patients (if any) categorised as IBC patients and differentiated from other Stage III and IV breast cancer patients according to urgency?
- According to numerous clinical case studies, IBC has a much higher risk of localised recurrence while awaiting radiation. The longer Jennifer remains on Trastuzumab, the more effect it has on her joints and tissue, liver and heart. Without it though, there is a proven higher risk of localised cancer recurrence and metastasis than with other Stage 3 cancers. Surely this should warrant a higher triage status than those cases?
- Jennifer has never used her bipolar condition as an excuse to improve her cancer treatment but has declared it on every cancer document she has completed. What is the government/hospital policy regarding cancer treatment or therapy for patients with additional handicaps, conditions and disabilities? Is any consideration taken regarding how delays in treatment could affect patients' mental or physical health and wellbeing?
- What other recurrence-restricting treatments could be offered by Charlotte Maxeke should Jennifer not be able to cover the costs of any additional Trastuzumab treatments needed before radiation finally takes place? Do any even exist?
- Why is there not a referral process for radiation treatment between centres in place when, as you stated, waiting times are lower in other centres like Steve Biko in Pretoria?

Answers to these questions do have bearing on both Jennifer's health and the ongoing delays in her treatment. Clarification on current processes, and reasons for them, would provide Jennifer with a greater understanding and, potentially, some form of acceptance.

No Solutions in Sight as Yet

Jennifer Blowers still feels let down for the following reasons:-

- There is no recognition of IBC in government health protocols. In fact, **IBC is hardly mentioned** in government breast cancer guidelines and policies. They view the disease in exactly the same way as other forms of less aggressive breast cancers. The option of targeted treatment is available to regular breast cancer sufferers if their cancers get diagnosed in time (Stage I or II). **Jennifer never had this option** as IBC, even when diagnosed early, gets an immediate Stage III classification.
- Gauteng Health Department oncology communication about accepted protocols is not given on time. The implications of **these delays can be life threatening**. IBC patients need the knowledge because of the rapid growth rates of IBC tumours so, on diagnosis, oncologists should be offering an option of prescriptions for patients to potentially secure targeted drugs privately. Nobody else is better positioned to advise on whether government treatments will be available in specific cases.
- There is **no definitive triage system for IBC patients**. They get treated as regular Stage III or IV breast cancer patients, which is short-sighted and unfair as there can never be an initial Stage I or II diagnosis. Hence, this excludes IBC patients from access to targeted medication like Trastuzumab.
- Communication between breast cancer-related departments is not solving problems. The CMJAH Radiation Oncology Department stated that regular multidisciplinary meetings do take place. Why then, are breast clinics and medical oncology departments encouraging the patients themselves to secure radiation dates? An outline of multidisciplinary meetings between breast surgery, radiology, pathology and oncology departments appears on page 19 of the Department of Health's **Breast Cancer Control Policy** (updated 07/21). Why is a consensus of opinion on patient treatment not being reached?
- The expected radiation delays may not only negatively affect the status of Jennifer's cancer, but also her financial position. Dr. Mayet has suggested that Jennifer fund a further 5 Trastuzumab treatments over and above the 6 months of government-funded ones. This will cost Jennifer **upwards of R25000,00**. Should there be further radiation delays, she would need to pay over **R5000 per extra treatment** in an attempt to maintain her current cancer status.

- The Trastuzumab treatment has a lasting impact on Jennifer's joints, tissue, liver and heart. The **severity of this will only increase** with further administering of the drug, possibly even disqualifying her from eventual radiation treatment.
- Jennifer receives **no consideration as a Bipolar Mood Disorder sufferer** despite her condition being clearly visible in her file. She has not drawn any attention to this before but her ongoing cancer treatment is wearing her down, both in a physical and psychological way.
- According to statistics, IBC has a **higher incidence rate among black women** than white. Considering South Africa's population demographic, along with the literacy and education levels among many patients using government health facilities, how many patients even question their cancer treatment protocols? Jennifer is fortunate to be well-educated and have the ability to research or she might not even have had surgery yet. In the recent meeting at CMJAH Jennifer expressed **concern about those who aren't able to speak up or fight** for themselves. The only response she received was an unnecessary private comment afterwards that appeared to target her race. For a less fortunate IBC patient in South Africa, the above factor could be a distinct difference between living and dying.

So Jennifer Blowers remains let down. She is very tired too. She has to fight for her life against Inflammatory Breast Cancer whilst also fighting for effective treatment. Her body is being ravaged by the effects of 12 months of chemotherapy and she is having to adapt to life without her breasts. The psychological impact of this alone is huge but Jennifer also has the added pressure of maintaining a positive mental state due to her Bipolar Mood Disorder. She feels like the Gauteng Department of Health and CMJAH are doing nothing to make her life easier. Instead they are only **compounding her struggles**.

Mr. Jack Bloom, the **DA Shadow MEC for Health** in Gauteng, has recently been contacted about Jennifer's case and the current plight of government-sector IBC patients in general. Bloom has submitted an official question to the **Gauteng Provincial Legislature** in this regard. A reply within 3 weeks is obligatory.

Conclusion

South Africa, and more specifically, the Gauteng province, is in the midst of an oncology crisis. Breast cancer cases among women have risen by nearly 2000 to over 10000 cases per year between 2014 and 2019 (the most current NCA report available according to

CANSA). As there is no distinction made, the number of Inflammatory Breast Cancer cases that exist cannot be accurately stated here.

However, by taking a percentage of the 2019 breast cancer cases (the World average puts IBC at between 1% and 5% of breast cancers), a reasonable assumption can be made that between 100 and (at least) 300 women are being treated for the disease in South Africa.

With certain private cases existing, those being treated according to National Department of Health protocols are possibly slightly less but, in essence, does this really matter? A life is a life and whether a single patient or 150 million patients exist makes that single life no less of a priority.

Jennifer Blowers **has only one life** and deserves the treatment of that single life to be taken seriously, as do all of the others being treated at government level. By not affording Jennifer (and other IBC patients like her), the options to treat her rare and aggressive form of breast cancer in an effective manner befitting the serious protection of her life, the government is potentially taking away her **basic human right** to live.

Non-adherence to the international recognition given to IBC as a different and devastating form of breast cancer, and the refusal to treat it as such, is akin to sentencing innocents IBC patients to death. The statistics back up this statement - the 5-year survival rate for people with Inflammatory Breast Cancer is 41% (**cancer.net**) - and that's when the majority receive suitable treatment!

The South African judicial system no longer applies the death penalty as it infringes on a person's basic human rights. So how… why… is the Government still placing Inflammatory Breast Cancer patients on death row?

(Image: Citizen article on Gauteng Health R500 Million Linac Accelerator Investment)

New Radiotherapy Machines in Storage while Gauteng Patients are Turned Away

Read Jennifer Blowers' personal description of her first year with Inflammatory Breast Cancer **here**.

Please support and assist Jennifer through her **BackaBuddy** campaign.

This article is available online at **CopyFounder**

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