



CANCER ALLIANCE ADVOCACY TOOLKIT

PRIORITY AREA #3: PATIENTS' RIGHT TO HEALTHCARE

OUR CONSTITUTION GUARANTEES ALL SOUTH AFRICANS THE RIGHT OF ACCESS TO HEALTHCARE SERVICES. BUT IN SPITE OF SOUTH AFRICA BOASTING THE BIGGEST HEALTH BUDGET IN AFRICA, TOO OFTEN POOR SERVICE DELIVERY FOR CANCER PATIENTS IS SEEN IN MUCH OF THE STATE SECTOR.

THE FACTS

Too many patients, with cancer that could be curable, are slipping through the cracks and dying unnecessarily. This is as a result of a combination of lack of awareness, lack of resources, and lack of access to affordable, effective and quality cancer services [1].

SO WHAT DO WE NEED?

We need to see cancer patients, their families, communities and civil society stand up and demand their rights in terms of the following:

- **The Constitution:** Section 27 of the Constitution says every person has the right to have access to healthcare services. This puts the onus on the government to, among other things, respect this right of access by not unfairly or unreasonably getting in the way of people accessing existing health services. Government must also fulfil this right by creating the right conditions for people to access such healthcare, by providing positive assistance, benefits and effective healthcare services. [2]
- **The National Health Act:** This requires the Health Minister to, within the limits of available resources, endeavour to protect, promote, improve and maintain the health of the population. The Minister must also determine the policies and measures necessary to do so. The National Department, along with the



provincial and municipal departments, must establish health services as required by the Act, in an equitable manner. [3]

- **The Children’s Act 38 of 2005** (as amended by Act 41 of 2007) stipulates that parents and their children have the right to information and treatment, and that informed consent is paramount. Healthcare workers need to be trained to ensure both the child and parents enjoy the right to informed choice, as enshrined in the Act. [4]
- **The Cancer Regulation of 2011** stipulates that cancer should be registered. This would secure a true reflection of cancer morbidity, which would in turn assist policy and decision makers to plan for cancer services in South Africa. Every cancer patient should be made aware of this crucial regulation, and demand that their information is captured in the National Cancer Registry.
- **The patent law of South Africa:** South Africa must better balance its patent law to prioritize people’s rights to access medicine, rather than commercial patent rights.
- **The National Patients’ Rights Charter:** Launched in 1999 by the National Department of Health, this Charter is not a law, but sets out guidelines which healthcare workers and patients are expected to follow. The Charter says all healthcare workers, including doctors and nurses, must treat all patients with human dignity, respect, courtesy, patience and tolerance. It also explains the Constitutional right of access to healthcare services (above) so patients know what they have the right to expect from state healthcare services. [5]
- **Batho Pele (People First):** This initiative aims to get people working in public services, including healthcare, to become more service-oriented, and to strive for excellence towards continuous service delivery improvement. The two primary functions within the framework, for purposes of healthcare, include service delivery to patients, and the ability to hold individual healthcare personnel accountable for poor service delivery. [6]

WE CANNOT ACHIEVE THIS WITHOUT:

- Education so that patients understand their right to complain, and the procedures to do so.
- Buy-in from civil society groups willing to join the fight for the rights of cancer patients.
- The government taking responsibility for affording cancer a priority disease status.

HOW CAN WE MEET THE CHALLENGE?

CHALLENGE 1: PATIENT EDUCATION:

Patient-centred care is a human right, and the right to human dignity should be the standard for all cancer patients. But instead of knowing their rights, and being empowered to speak up for those rights, their voices are seldom heard. This threatens the constitutional right of cancer patients to dignity of care for all.

Patients must also be educated to complain about poor service delivery in order to achieve remedial action. Currently, there are processes to follow to lodge complaints, but few patients are aware of this, or fear discrimination from staff if they do complain.

Cancer is the third biggest killer of South Africans [6], and that should be enough to get the disease the priority it deserves. Instead, in spite of South Africa having the biggest health budget in Africa, poor service delivery is unacceptably commonplace in much of the state sector.

Qualitative research into the grassroots experiences of cancer patients and their families [7] found the following challenges were faced by patients:

- Late referrals.
- Poor service delivery.
- Poor treatment outcomes.
- Lack of compliance due to poor services.
- Lack of information.
- Lack of psychosocial support across the trajectory of care.
- Lack of patient-centred approach to providing healthcare services.

Advocacy is essential to raise public awareness to ensure patients access cancer services timeously, and to educate the public healthcare personnel to be better equipped to identify and respond when patients present with cancer symptoms. [8]

CHALLENGE 2: ACCEPTING RESPONSIBILITY

Communities, civil society, NGOs and the government all need to accept responsibility for the challenge of delivering locally appropriate, effective solutions that provide sustainable quality cancer services.

Just as the Treatment Action Campaign changed the face of HIV/Aids treatment and care in South Africa, the same needs to be done for cancer. Although far fewer South Africans are affected by cancer than HIV/Aids, a similar strategy is essential to change the status quo.

Just a few examples of the need for urgent intervention become obvious from the following:

Nationally, most cancer treatment and diagnostic tools, like CT scans, remain centralized at provincial and specialist hospitals, requiring patients to travel hundreds of kilometres from rural areas to access care.

In some provinces, one CT scanner serves many referring hospitals. This can result in patients who have been diagnosed with cancer waiting a month or even longer for a scan to simply confirm the location of the cancer in their bodies. [9]

The result? People die unnecessarily from treatable cancers.

In Kenya, efforts to work towards a dedicated cancer bill began in 2009 thanks to the efforts of the Kenya Cancer Association. After a long road and through enormous support from members of that Parliament and Kenya's Ministry of Health, the Cancer Prevention and Control Act of 2012 was finally signed into law in July 2012 and updated in 2016. [10]

There is no reason why similar action cannot be successful in South Africa. South African stakeholders need to be the change they want to see. An innovative approach is however essential to determine cost-effective strategies within the budget constraints of the South African healthcare system.

GOOD HEALTH IS YOUR RIGHT

Everyone has the right to good health and quality healthcare, including:

- Living in a healthy and safe environment.
- Access to affordable, quality healthcare.
- Choosing the healthcare services you prefer to use.
- Receiving appropriate treatment from a qualified healthcare professional.
- Knowing that your personal information is treated confidentially.
- Being fully informed about any illness, diagnostic procedures, proposed treatments and related costs.
- Choosing to accept or refuse treatment.
- Getting a second opinion, where appropriate.
- Receiving ongoing care from your chosen healthcare provider.

You also have the right to complain about healthcare services that either violate your rights to good health or breach ethical standards, to have your complaint investigated, and to receive a full response thereafter.

WHAT CAN YOU COMPLAIN ABOUT?

Healthcare professionals registered with the Health Professions Council of SA are required to uphold prescribed standards of professional and ethical behaviour. You are entitled (and encouraged) to lodge a complaint with the HPCSA in respect of:

- Unauthorized advertising.
- Incompetence in treating patients.
- Over-servicing patients.
- Charging excessive fees.
- Criminal convictions.
- Insufficient care of patients.
- Improper relationships.
- Racial discrimination.
- Improper conduct.
- Rude behaviour towards patients.
- Performing surgical procedures without the patient's informed consent.
- Prescription of specific medicine to maintain the dependency of a patient.
- Disclosing information about the patient without his/her permission.

REFERENCES

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SOCIAL MEDIA GUIDE

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HASHTAGS FOR THIS CAMPAIGN

#LetsTalkAboutCancer

#RightToHealth

SUGGESTED POSTS

We need to see cancer patients, their families, communities and civil society stand up and demand their rights **#LetsTalkAboutCancer**

Section 27 of the Constitution says every person has the right "to have access to healthcare services" **#LetsTalkAboutCancer #RightToHealth**

The Minister of Health has a duty to protect, promote, improve and maintain the health of the population **#LetsTalkAboutCancer #RightToHealth**

Healthcare workers need to be trained to ensure both the child and parents enjoy the right to informed choice **#RightToHealth**

Cancer patients must demand that their information is captured in the National Cancer Registry **#LetsTalkAboutCancer #RightToHealth**

South Africa must better balance its patent law to prioritize people's rights to access medicine, rather than commercial patent rights **#LetsTalkAboutCancer**

The National Patients' Rights Charter gives guidelines that healthcare workers and patients are expected to follow **#LetsTalkAboutCancer**

Healthcare workers, including doctors and nurses, must treat patients with dignity, respect, courtesy, patience and tolerance. Does this happen? **#RightToHealth**

Batho Pele (People First) makes individual healthcare personnel accountable for poor service delivery **#RightToHealth**

Patient-centred care is a human right but patients are not making their voices heard
#LetsTalkAboutCancer #RightToHealth

You have the right to complain about poor service delivery. It is time to speak up!
#LetsTalkAboutCancer #RightToHealth

South Africa has the biggest health budget in Africa, so why is poor service delivery the norm in much of the state sector? **#LetsTalkAboutCancer**

Everyone has the right to good health and quality healthcare **#LetsTalkAboutCancer #RightToHealth**