



Cancer Association of South Africa (CANSA)

CANSA Position Statement on Patient Rights Including the Rights of Caregivers

Preamble

At various points in their lives, every one of the inhabitants of South Africa will need to access health care services. Every single South African citizen today has a constitutional right to such access. This was, however, not always the case.

For the majority of the South African population, the public health services that were offered were often of questionable quality. A person's racial classification had a significant impact on his or her ability to access health care services as well as the quality of health care that was provided. Many people's rights were violated, especially their rights to equality, dignity and privacy.



[Picture Credit: Patient Rights]

The end of apartheid, however, has not seen an end to all of these inequalities. Many inequalities still exist and are strongly influenced by service delivery and socio-economic factors such as class and income. In South Africa, race, class and income remains closely linked. Since 1994, various laws and policies have been put into place to make sure that the rights of all people who need to access health care services are respected, protected, promoted and fulfilled. These laws and policies are specifically aimed at improving access to, and the quality of public health services, as well as ensuring that more people are able to access private health care services (Swanepoel; Section 27).

A Patient Rights Charter for South Africa

In recognition of the historical past of South Africa and in total support of the Constitution of The Republic of South Africa, 1996 (Act No 108 of 1996) the Cancer Association of South Africa (CANSA) noted the introduction of, and supports, the following Patients' Rights Charter developed by the National Department of Health, in consultation with various other bodies.

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Patients' Rights Charter

1. Introduction

1.1 For many decades the vast majority of the South African population has experienced either a denial or violation of fundamental human rights, including rights to health care services.

1.2 To ensure the realisation of the right of access to health care services as guaranteed in the Constitution of the Republic of South Africa, 1996, the Department of Health is committed to upholding, promoting and protecting this right and, therefore, proclaims this PATIENTS' RIGHTS CHARTER as a common standard for achieving the realisation of this right.

2. Patients' Rights

2.1 Healthy and Safe Environment

Everyone has the right to a healthy and safe environment that will ensure their physical and mental health or well-being, including adequate water supply, sanitation and waste disposal, as well as protection from all forms of environmental danger, such as pollution, ecological degradation or infection.

2.2 Participation in Decision-making

Every citizen has the right to participate in the development of health policies, whereas everyone has the right to participate in decision-making on matters affecting one's own health.

2.3 Access to Health Care

Everyone has the right to access to health care services that include:

- receiving timely emergency care at any health care facility that is open, regardless of one's ability to pay;
- treatment and rehabilitation that must be made known to the patient to enable the patient to understand such treatment or rehabilitation and the consequences thereof;
- provision for special needs in the case of new-born infants, children, pregnant women, the aged, disabled persons, patients in pain, persons living with HIV or AIDS patients;
- counselling without discrimination, coercion or violence on matters such as reproductive health, cancer or HIV/AIDS;
- palliative care that is affordable and effective in cases of incurable or terminal illness;
- a positive disposition displayed by health care providers that demonstrates courtesy, human dignity, patience, empathy and tolerance;
- health information that includes information on the availability of health services and how best to use such services, and such information shall be in the language understood by the patient.

2.4 Knowledge of One's Health Insurance/Medical Aid Scheme

A member of a health insurance or medical aid scheme is entitled to information about that health insurance or medical aid scheme and to challenge, where necessary, the decision of such health insurance or medical aid scheme relating to the member.

2.5 Choices of Health Services

Everyone has a right to choose a particular health care provider for services or a particular health facility for treatment, provided that such choice shall not be contrary to the ethical standards applicable to such health care provider or facility.

2.6 Treated by a Named Health Care Provider

Everyone has a right to know the person that is providing health care and, therefore, must be attended to by only clearly identified health care providers.

2.7 Confidentiality and Privacy

Information concerning one's health, including information concerning treatment may only be disclosed with informed consent, except when required in terms of any law or any order of court.

2.8 Informed Consent

Everyone has the right to be given full and accurate information about the nature of one's illnesses, diagnostic procedures, the proposed treatment and the costs involved.

2.9 Refusal of Treatment

A person may refuse treatment and such refusal shall be verbal or in writing, provided that such refusal does not endanger the health of others.

2.10 A Second Opinion

Everyone has the right on request to be referred for a second opinion to a health provider of one's choice.

2.11 Continuity of Care

No one shall be abandoned by a health care professional who or a health facility which initially took responsibility for one's health.

2.12 Complaints About Health Services

Everyone has the right to complain about health care services, to have such complaints investigated and to receive a full response on such investigation.

3. Responsibilities of the Patient

Every patient or client has the following responsibilities:

- to take care of his or her own health
- to care for and protect the environment
- to respect the rights of other patients and health care providers
- to utilise the health care system properly and not to abuse it
- to know his or her local health services and what they offer
- to provide health care providers with relevant and accurate information for diagnostic, treatment, rehabilitation or counselling purposes
- to advise health care providers of his or her wishes with regard to his or her death
- to comply with the prescribed treatment or rehabilitation procedures

- to enquire about the related costs of treatment and/or rehabilitation and to arrange for payment
- to take care of the health records in his or her possession

The Charter is subject to the provisions of any law operating within the Republic of South Africa and to the financial means of the country.

The Rights of Children in Healthcare in South Africa [Approved by the Organisation for Paediatric Support in South Africa (OPSSA)]

[Picture Credit: Children's Rights]

As a child in a healthcare facility in South Africa, I have the right:

- to expect that everything that people are doing will be in my best interest
- to get all the support I need to develop emotionally, physically, socially and spiritually to the best of my abilities
- to expect people to know my name and to be told the names of the people working with me
- to expect that the people working with me have the necessary skills to work with children
- to be valued and treated with love
- to know that my gender, culture, race, ethnicity and religion will be respected at all times
- to have my parents or caregivers with me as far as possible to take care of me and for support
- to be cared for in a child-friendly environment designed to meet my specific needs and free of any unnecessary emotional stress
- to be able to play whenever I feel like it
- to know exactly what is going to happen and to have it explained to me so that I can understand
- to be included in discussions and not to have people talking about me as if I am not in the room
- to make my own decisions when appropriate and to know that my views are important to the people caring for me
- to have my privacy respected at all times
- not to have my photo taken and/or my name and illness discussed outside the healthcare facility without my permission
- to cry if I need to when I'm hurt or scared
- not to experience unnecessary pain or discomfort



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The Rights of Nurses

As an employer of both professional and enrolled nurses, the Cancer Association of South Africa (CANSA) also recognises and supports the following rights of nurses as announced by the South African Nursing Council (SANC):

[Picture Credit: Nurses' Rights]

The Rights of Nurses

In carrying out his/her duty to patients, the nurse operates within the ethical rules governing the profession and his/her career scope of practice.

The confirmation of the rights of the nurse is, therefore, not an end in itself, but a means of ensuring improved service to patients. To enable the nurse to provide safe, adequate nursing, he/she has the right to:

- practise in accordance with the scope which is legally permissible for his/her specific practice;
- a safe working environment which is compatible with efficient patient care and which is equipped with at least the minimum physical, material and personnel requirements;
- proper orientation and goal-directed in-service education in respect of the modes and methods of treatment and procedures relevant to his/her working situation;
- negotiation with the employer for such continuing professional education as may be directly or indirectly related to his/her responsibilities;
- in the case of a registered person, equal and full participation in such policy determination, planning and decision-making as may concern the treatment and care of the patient;
- advocacy for and protection of patients and personnel for whom he/she has accepted responsibility;
- conscientious objection, provided that:
 - the employer has been timeously informed in writing
 - it does not interfere with the safety of the patient and/or interrupt his/her treatment and nursing
- refuse to carry out a task reasonably regarded as outside the scope of his/her practice and for which he/she has insufficient training or for which he/she has insufficient knowledge or skill;
- not to participate in unethical or incompetent practice;



- written policy guidelines and prescriptions concerning the management of his/her working environment;
- refuse to implement a prescription or to participate in activities which, according to his/her professional knowledge and judgement, are not in the interest of the patient;
- have disclosed to him/her the diagnosis of patients for whom he/she accepts responsibility;
- a working environment which is free of threats, intimidation and/or interference;
- a medical support or referral system to handle emergency situations responsibly.
- In addition to the above, the nurse is entitled to his/her rights in terms of the Constitution of the Republic of South Africa and relevant labour legislation; provided that the exercising of such rights does not put at risk the life or health of patients.

The Rights and Responsibilities of Volunteers

CANSA, as a volunteer-driven organisation, notes and supports the following rights and responsibilities of volunteers.

As there is currently no South African Charter on the Rights and Responsibilities of Volunteers, an abbreviated version of the European Charter on the Rights and Responsibilities of Volunteers is used as the basis for the CANSA Position Statement on Patient Rights.

The European Charter on the Rights and Responsibilities of Volunteers

Preamble

We, the supporters of this Charter, believe that access to volunteering and active citizenship opportunities are rights, not privileges. We are deeply convinced that every person has the right to volunteer anywhere in the world. First and foremost – volunteers need to be empowered with the rights that match their needs and fit their duties.

[Picture Credit: Volunteer]



This Charter promotes the role of participatory organisations, which means that volunteers must have access to the decision-making processes of the organisation and are, therefore, actively part of the organisation's life, as the main providers for volunteering.

Definition of a Volunteer

A volunteer is a person who carries out activities benefiting society, by free will. These activities are undertaken for a non-profit cause, benefiting the personal development of the volunteer, who commits their time and energy for the general good without financial reward. The activities provided by volunteers are undertaken for a non-profit cause and does not replace paid staff.

The Rights of Volunteers

Everyone who is doing a volunteering activity is entitled to have the status of 'Volunteer', and, if they wish, they should be entitled to the basic rights listed below.

- Volunteers are entitled to full protection of their human rights when carrying out the volunteering activity.
- Every person is entitled to equal access to volunteering opportunities and protection against all kinds of discrimination such as on the grounds of age, gender, sexual identity, race, colour, language, disability, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status and shall not be discriminated against on basis of their background or beliefs.
- No one shall be restricted by law from participating in a volunteering activity of their choice, as long as the volunteering is carried out in respect of Human Rights and contributes to the public good.
- All volunteers shall be informed about their rights and responsibilities.
- Every volunteer has the right to social protection during the volunteering activity in the form of health care and liability insurance.
- Every volunteer has the right to reconcile their volunteering activity with their private and working life, and thus can achieve a certain amount of flexibility during the volunteering activity. Every volunteer is furthermore entitled to refuse tasks that would go against their beliefs and/or convictions.
- Every volunteer is entitled to the reimbursement of expenses incurred in relation to the voluntary activity, respecting the different levels of reimbursement that result from the diversity of voluntary activities. These reimbursements shall be excluded from any form of taxation.
- Every volunteer is entitled to be treated according to the existing norms, principles, standards and goals of volunteering policies.
- Every volunteer is entitled to a coherent task description that allows them to implement the volunteering activity with a clear understanding of its aims and objectives. The task description should be, to the furthest extent possible, developed and agreed on together between the volunteering provider and the volunteer and, if needed, should be updated during the volunteering activity. Furthermore, it should be defined that volunteers and paid staff have complementary roles and the volunteering providers must ensure that good cooperation exists between these two personnel categories.

- Every volunteer is entitled to support and feedback throughout the volunteering activity. This includes preparation of the activity, personal guidance and assistance during the implementation of the activity, proper evaluation and debriefing following the activity and full support in the realisation of the required follow-up activities.
- Every volunteer has the right to participate in the decision-making process regarding the volunteering activity at the most appropriate level. In addition, each volunteer should have access to the organisation's democratic decision-making processes. Each volunteer should have some ownership of the project through co-decision in the process implementation and the right to participate in the democratic processes related to the project.

The Responsibilities of Volunteers

- Every volunteer respects the rules of law and non-discrimination throughout their voluntary activity.
- Every volunteer has the responsibility to respect the integrity, mission, objectives and values of the volunteering provider.
- Every volunteer respects the commitments that are made with the volunteering provider regarding the amount of time and effort that have been commonly agreed to be put in the volunteering activity and the quality that has to be delivered.
- Every volunteer has the responsibility to participate in training offered that are relevant for the volunteer and are related to skills needed in order to carry out the agreed tasks. The training shall be free of charge to the volunteer.
- Every volunteer respects the confidentiality of (organisational) information, in particular regarding legal affairs and concerning personal data of members, staff and beneficiaries of voluntary activities.
- Every volunteer understands that volunteering aims towards benefits for the common good or society.
- Every volunteer cooperates with other volunteers within the organisation, where relevant and contributes to the organisation's sustainability through communication with other and a hand-over at the end of their engagement.

The Position of the Cancer Association of South Africa (CANSA) Regarding Cancer Survivors

The Cancer Association of South Africa (CANSA) believes that no rights can exist in human society without reciprocal responsibilities mentioned in this document. CANSA, therefore, believes that every person diagnosed with cancer must be recognised as a cancer survivor with entitlement to the following rights inclusive of relevant reciprocal responsibilities:



[Picture Credit: Cancer Survivor]

- to have an accurate, clearly explained diagnosis conveyed as early as possible to prevent any unnecessary anxiety caused by having to wait
- to have the diagnosis conveyed and explained in a compassionate manner by a qualified health professional
- to be provided privacy and total confidentiality concerning health, including information concerning treatment which may only be disclosed following informed consent, except when required in terms of any law or any order of a court
- to have an interpreter available if at all possible (and when applicable) to assist the patient in understanding anything pertaining to his/her diagnosis, treatment, and support or care
- to ask questions relevant to the diagnosis that was conveyed
- to be provided the right to a second opinion
- to be informed about all cancer treatments available in South Africa relevant to a specific cancer diagnosis
- to have the right to maintain hope and to be supported in that hope by the whole medical, support and care team
- to have the right to include or exclude family members or significant others in discussions with the medical, care or support teams
- to have access to, and to receive the best standard of health care, specific to a particular cancer diagnosis inclusive of:
 - receiving timely emergency care at any health care facility that is open, regardless of the ability to pay
 - provision for special needs in the case of children, pregnant women, the aged, persons with disabilities, patients in pain, persons living with HIV or AIDS patients
 - rehabilitation information to be made known to the patient to enable the patient to understand such rehabilitation and the consequences thereof
 - counselling without discrimination or coercion
 - palliative care that is affordable and effective in cases of incurable or terminal illness
 - a positive disposition displayed by health care providers that demonstrates courtesy, human dignity, patience, empathy and tolerance
 - health information that includes information on the availability of health services and how best to use such services - such information shall be in a language understood by the patient
- the right to access of an acceptable standard of care based on need and not the ability to pay for it
- the right to access of the best treatment and care available no matter age, race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, disability, religion, conscience, belief, culture, language or birth
- to be involved in the planning of the cancer treatment, care and support regimen
- to have continuity of treatment, care and support - no one shall be abandoned by a health care professional or a health facility which initially took responsibility without appropriate referral or hand-over
- to have a say together with health care professionals in treatment, care and support
- to have a say in choosing the medications that are prescribed
- to have wishes expressed in a living will (or similar document) implemented to its full extent

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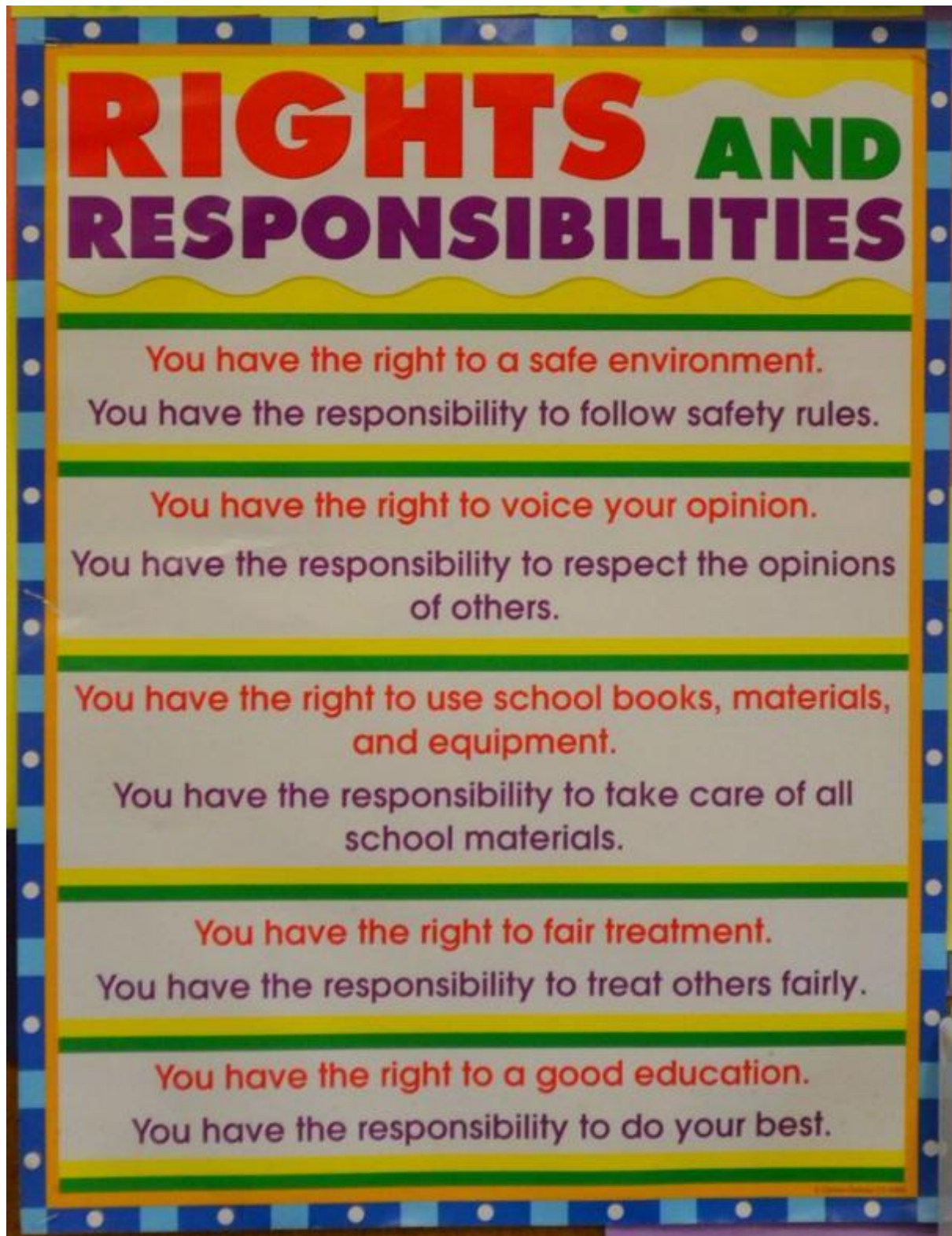
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- to be kept free from pain irrespective of whether a desire has been expressed not be kept alive on life support or not
- to receive treatment, care and support based on a multidisciplinary approach which may include – apart from the medical team's assistance – support from other specialists or support systems
- to have the right to refuse treatment. Such refusal shall be verbal or in writing, provided that such refusal does not endanger the health of others
- to be provided with the name(s) and contact details of members of the treatment, care and support team who may be able to answer urgent questions at times other than scheduled consultations
- to be provided access to all medical records, including radiology reports, pathology reports, histopathology reports, genetic analysis, digital copies of all scans and any other relevant health information
- to express an opinion on the treatment, care and support received at an institution or by individuals without fear of retribution
- to be informed of relevant clinical trials that may be relevant to a particular cancer diagnosis



<https://za.pinterest.com/explore/children's-rights-and-responsibilities/?lp=true>



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* A Caregiver is defined as:

1. An individual, such as a physician, nurse, or social worker, who assists in the identification, prevention, or treatment of an illness or disability.
2. An individual, such as a parent, foster parent, a head of a household or any other individual who attends to the needs of a child or dependent adult.
(The Free Dictionary).

[Picture Credit: Caregiver]



Medical Disclaimer

This Position Statement is intended to provide general information only and, as such, should not be considered as a substitute for advice, medically or otherwise, covering any specific situation. Users

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