HPCA
CARE & SUPPORT
Hospice Palliative Care Association of South Africa

whpca
worldwide hospice palliative care alliance



PALLIATIVE CARE FACT SHEET FOR MEDIA IN SOUTH AFRICA



WHAT IS HOSPICE AND PALLIATIVE CARE?

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.[1]

Palliative care affirms life and regards dying as a normal process and intends neither to hasten nor to unduly postpone death.

Hospices are community-based organisations providing palliative care either at the hospice, or in people's homes in the community.

The Hospice Palliative Care Association of South Africa (HPCA) is a national NGO, formed in 1987 to represent, co-ordinate, facilitate and promote the activities and interests of its member Hospices and Palliative Care Providers in South Africa.

PALLIATIVE CARE AND THE GLOBAL GOALS

The Sustainable Development Goals (SDGs), otherwise known as the Global Goals, are a universal call to action to end poverty, protect the planet and ensure that all people enjoy peace and prosperity.[2]

> **"Low availability and accessibility of palliative care globally for people living with life-limiting illness is a prominent example of extreme inequality and injustice."**



Governments, civil society and citizens must be empowered to work towards equitable access to palliative care as part of the Global Goal for Health.

Palliative care is vital to achieve healthy lives and well-being for all at all ages and thus an essential part of Global Goal 3: Good Health and Well-being.

Palliative care is a critical component of Universal Health Coverage, a target under Global Goal 3.

WHAT IS UNIVERSAL HEALTH COVERAGE?

> **“Palliative care is a recognised component of the right to the highest attainable standard of health.”**

Universal health coverage (UHC) means that all people have access to the health services they need (prevention, promotion, treatment, rehabilitation and palliative care) without the risk of financial hardship when paying for them.[3]

> **“People who need palliative care have some of the greatest healthcare needs. They must be included in UHC.**

Palliative care is an essential part of UHC as defined by the World Health Organization.

UHC means everyone must be able to access the health services they need, including palliative care, without being forced into financial hardship.



PALLIATIVE CARE IS PART OF THE RIGHT TO HEALTH



> **“Palliative care is a recognised component of the right to the highest attainable standard of health”**

which is protected in Article 12 of the International Covenant on Economic, Social and Cultural Rights,[4] and in Article 24 of the Convention on the Rights of the Child.[5]

Article 25 of the UN Convention on the Rights of Persons with Disabilities[6] – Right to Health & Healthcare states that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability, and that government should provide health services needed by persons with disabilities specifically because of their disabilities.

Access to adequate pain relief is protected under Article 7 of the International Covenant on Civil and Political Rights, which prohibits torture, inhuman or degrading treatment or punishment.[7]

In 2014, the World Health Assembly passed Resolution WHA 67.19: 'Strengthening of palliative care as a component of comprehensive care throughout the life course', calling on WHO and Member States to improve access to palliative care as a core part of health systems.[8]





NATIONAL STEERING COMMITTEE ON PALLIATIVE CARE

Minister of Health, Dr Aaron Motsoaledi, appointed a committee to guide the South African Department of Health to implement, monitor and evaluate progress towards achieving a national policy on palliative care and the WHA 67.19 recommendations. These are:

1. to develop and implement palliative care policies;
2. to ensure adequate domestic funding and allocation of human resources for palliative care initiatives;
3. to provide basic support to families, community volunteers and other individuals acting as caregivers, under the supervision of trained professionals;
4. to aim to include palliative care as an integral component of the ongoing education and training offered to care providers, in accordance with their roles and responsibilities;
5. to assess domestic palliative care needs, including pain management medication requirements, to ensure adequate supply of essential medicines in palliative care;
6. to review and revise national and local legislation and policies for controlled medicines,
7. to update, as appropriate, national essential medicines lists;
8. to foster partnerships between governments and civil society, including patients' organizations, to support the provision of services for patients requiring palliative care; and
9. to implement and monitor palliative care actions included in WHO's global action plan for the prevention and control of non-communicable diseases 2013–2020.



KEY STATISTICS

- Millions of people worldwide living with life-limiting illness are living and dying in avoidable pain and distress.
- 61.5 million people experience serious health related suffering worldwide.[9]
- Only 10% of those who need palliative care worldwide can access it.[10]
- 75% of the world has no access to essential medicines for pain
- relief.[11]

“Approximately 350-400,000 people need palliative care in South Africa in the last year of their life.[12]”

- There are also people who need palliative care earlier in the illness; this estimate has not yet been quantified.
- The average need for palliative care for the South African population is 698.5 persons per 100,000; close to 1 out of every 143 people every year.[12]

> **“South African hospices cared for 100,236 patients last year.[12]”**

- The National Policy Framework and Strategy for Palliative Care aims to ensure integration of palliative care into public health facilities. This will improve access to palliative care for all South Africans. Palliative Care is included in National Health Insurance.
- The main diseases and conditions requiring palliative care in South Africa are:
  - Communicable diseases such and HIV and Tuberculosis.
  - Non-Communicable Diseases: cancer, neurological diseases such as Multiple Sclerosis and Motor Neurone Disease; heart failure; respiratory diseases such as emphysema; liver failure; renal failure; stroke; dementia.
  - Conditions such as stroke and dementia need palliative care in old age homes/frail care.
  - Most patients are admitted to hospice with cancer and HIV. Some hospices care for MDR TB patients and some care for patients with end-stage organ failure (heart, kidney, liver failure).[12]



- In recent years HPCA and members have also developed a focus on disability care because many of the clinical conditions mentioned above results in some form of disability and because of the long term palliative care needs of people with disability.[13]
- According to the WHO, 15% of the population has a disability
- The top six disease categories identified as predictable causes of death reflecting palliative care need in 2016 were:

    1. heart disease 36,398 (7.9% of deaths)
    2. TB 29,513 (6.5%)
    3. diabetes 25,255 (5.5%)
    4. cerebrovascular disease 23,137 (5.1%)
    5. HIV 21,830 (4.8%)[14]

- StatsSA report on cancer by type, but grouping neoplasms together (malignant and non-malignant), these diseases caused 9.3% of deaths.[14]









MYTHS AND FACTS ABOUT HOSPICE AND PALLIATIVE CARE

Myth: Palliative care and hospice care is only for people with cancer.

Fact: People with any terminal or progressive illness can benefit from palliative care at different points of their illness.

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Myth: Only the person who is ill can benefit from palliative care.

Fact: Palliative care is designed to help the family and friends of the person who is ill as well. If someone close to you has a terminal or progressive illness, it can have a big impact on you.

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Myth: Palliative care is just about helping people relieve pain and other physical symptoms.

Fact: The aim of palliative care is to help people with any terminal or complex, progressive illness have the best quality of life.

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Myth: Hospice hastens death.

Fact: Studies have shown that hospice care can actually increase survival for people with certain diagnosis when implemented early enough in the disease process.

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Myth: Hospice care is just for the elderly.

Fact: Hospice serves anyone facing a life-limiting illness, regardless of age.

WHY COVER A HOSPICE AND PALLIATIVE CARE STORY?

People directly affected by serious illness or life limiting conditions are true heroes. They are faced with an almost unbelievable amount of adversity, whether dealing with their own illness or that of a family member, friend or child. Their stories carry a high human interest value.

With the global focus on 'treatment and prevention' of diseases, people with serious illness or life limiting conditions are often overlooked by the healthcare system. Enabling these people to tell their stories can increase awareness among policymakers and lead to real change.



“Lack of or inadequate access to palliative care and pain relief is a scandal of huge proportions.”

Putting a human face to the story makes it personal and helps people to relate to this outrage. Covering these stories will help to hold those in power to account to their responsibility to ensure access to palliative care for all as part of UHC.

Palliative care issues are relevant to all citizens. We will all at some point experience serious illness either as a patient ourselves or in relation to a family member or close friend. These stories impact all South Africans. People have a right to palliative care and they have a right to know what their government is doing to ensure access to palliative care for all.



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