# The art of living and dying: A partnership story

Due to the Covid-19 pandemic, palliative care is now more in the mainstream eye than ever before. Dedicated to the holistic treatment of life-threatening diagnoses, as well as to the care end-of-life patients, those in the palliative care sector are experts in promoting quality of living and dignity in death - a topic that has become increasingly relevant since March 2021.

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This year's Hospice Week (dedicated to this sector, and taking place from 3 to 10 May), sees a focus on *role of partnership* in providing support and care for people with life-threatening illnesses. It seeks to recognise, share and celebrate achievements of both hospices and palliative care programmes together with their partners.[1]

A strong focus on the holistic – pain management, family support, spiritual counselling and much more - al forms part of the services that a palliative care team at a hospice provides. It is a partnership, between carers and patient, with the ultimate goal of ensuring that patients are able to live as fully as possible until they die.

Says Hospice East Rand: "Hospices are associated with dying, where they are in fact there to assist in the quality of life. We think this is often attributed to denial, resulting in a patient or family member reaching out us at the last minute instead of at the time of diagnosis. Our aim is to assist in the quality of life of the patie and to assist both patient and family members on their emotional journey as well."

"Our hospices report that the greatest challenge in their work is often that of acceptance by the person diagnosed as well as the family," says Ewa Skowronska, CEO of the Hospice Palliative Care Association (HPCA). "Fear of death, particularly in most western cultures, is very prevalent – the unknown, the preparation and the actual death process is not exactly a conversation that people easily have, but it's bee one that people have been forced into during this pandemic. It's a conversation that requires partnership a

openness between the person with a life-threatening diagnosis, professional health care team, families an loved ones. And it is a conversation about the importance of 'living' during this time as well! Even if that livi is to be short-term, it is an important aspect of the mortality conversation."

For Hospice Week this year, the Hospice Palliative Care Association are profiling the voices of the nurses and carers who understand the art of living and dying intimately.

Says Jamela Tiva of CHoiCe Trust: "My greatest fulfilments at work are seeing my patients pain free after two to three days and passing on pain-free; patients recovering from being bedridden and able to assist themselves and not depending on their family members and families coping with the life-threatening illnes of the patient because they understand the diagnosis and know how they can assist."

"We offer our services to everyone, regardless of whether they can afford to pay for it or not, as our vision **Quality Palliative Care** for all as everyone deserves to live well and when the time comes, to have a dignified death," continues Skowronska.

There are more than 103 hospice members of the HPCA, primarily self-funding via donations and grants, with minimal formal support. Over the last year, this has been very challenging as palliative care services have been needed more than normal, despite no formal funding in place.

The 2017 National Policy Framework and Strategy on Palliative Care (NPFSPC), approved by the National Health Council at the time, has still been implemented very scantily in the public healthcare system and, in many cases, is accorded lip service in the private system.

Says Sheila de Maroussem of Msunduzi Hospice Association: "Some of the biggest challenges we confro are that of poverty and the lack of resources, along with poor advocacy for palliative care in the Health sector."

“We are two sisters at Franschhoek Hospice and we are caring for an average of 100 patients. Our palliati care load can be demanding at times, with being on call every second weekend,” says Susan Swanepoel Franschhoek Hospice. “We have a large, demanding Department of Health contract with nine community health workers and the supervision, stats and work allocation is done by the two Palliative Care sisters as well.”

“The HPCA is actively involved in raising awareness of palliative care and what services hospices offers a well as working with Government and other organisations to make these services more financially sustainable and accessible to all. We’re all about partnerships – with the goal of making access to palliativ care for all South Africans,” says Skowronska.

Today only approximately 20% of people who need palliative care receive it, so there is still a lot that need to be done.

Concludes Skowronska: “The fourth edition of the Palliative Healthcare Standards was recognised internationally and accredited for four years by the global authority on standards development and assessment this year. South Africa has the opportunity to be a leader in palliative care, with decades of experience behind us and a proven track record for the importance of this speciality. We have seen an increased interest in healthcare professionals in understanding what palliative care encompasses during 2020 and 2021 and we are here to provide the mentorship and the service.”

If you would like to contribute to hospices, please visit: https://hpca.co.za/donate/. If you would like to cont a hospice, download the WeCare app for free to make contact or visit: https://hpca.co.za/ and click on *Fin a hospice*.

[1] *South African Government website - https://www.gov.za/hospice-week*


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