

From the desk of the CEO

So, there are two things to talk about in this edition of our newsletter.

The first is the amazing experience of our 40th anniversary celebrations. Our guest of honour was Dr Imtiaz Sooliman (Gift of the Givers) who gave a motivational address to those present.

I include here a summary of the CEO's address to the celebration, reflecting on where we have come from and some of the challenges that lie ahead of us.

CELEBRATING 40 YEARS OF CARE

A brief overview of Msunduzi Hospice

On occasions such as these, time is taken to reflect on history, where we come from, why we were established. These reflections often give rise to questions about our ongoing purpose and the need for organisations such as ours. The first meeting of the then Pietermaritzburg Hospice Movement was on 3 February 1983, following a community meeting in January of that year. Reading minutes can be interesting. Minutes dated 30 June 1983 have the following comment, after a discussion about a particularly difficult patient, "It was agreed that there is still a lot of confusion regarding the Hospice Movement and that the public will have to be educated." I see some smiles at these words. Words that are as applicable today, 40 years later. Not much has changed.

Please cast your minds back to the early 80's. A diagnosis of cancer was, for most people, a death sentence. The treatment of cancer was difficult and resulted in a great deal of physical pain for the patient. The patient often felt abandoned and alone. The family left with no resources on how to provide care or what care was needed. The Hospice movement as it was known, brought the principles of wholistic care, to bear on the patient and the family. Care that goes beyond the physical pain, but begins to address the emotional, social, and spiritual pain that a patient and their family may be going through. The founder of the modern Hospice

movement, Dame Cecily Saunders, spoke about total pain. This concept of total pain was defined as: the suffering that encompasses all of a person's physical, psychological, social, spiritual, and practical struggles.

And so, an intrepid band of volunteers in the early 80's began to share this understanding of care within the wider Pietermaritzburg community. Reading those early minutes one can get a sense of their passion and dedication. A small group of volunteers caring for a small group of patients. The initial group of patients numbered four. Yes, volunteers did everything. People with a passion for what they do. However, any organisation needs to develop and grow and be sustainable, and a complete reliance on volunteers needs to slowly give way to structures, policies, and staff. This requires income generation and related systems and structures. However, the passion must endure, it must be nurtured, it must grow.

Coming back to the minutes, one can begin to appreciate the processes involved in the establishment of this wonderful organisation



that has stood the test of time. The formation of a fund raising committee, the purchase of property, the employment of staff, milestone after milestone. Achievement after achievement.

Coming back to my opening point about education, Hospice care was always seen as terminal care and as such suffered from a lack of applicability. It is, perhaps, still seen as terminal care by many. Terminal care has limited

scope, particularly in the changing world in which we live here in South Africa and as part of the community of nations. While the terminology of Palliative Care had been around since the mid 1970's, in South Africa we still spoke about Hospice care. The change in philosophy from Terminal care to Palliative care coincided with the onset and growing awareness of the HIV/AIDS pandemic in South Africa.

HIV and its impact had been denied and ignored since the early 80's but exploded onto the scene in the mid 90's. The shift from working with those who had a few months to live and their particular needs to caring for those who, with the right treatment, could live an essentially normal life. I think also, that looking back we forget the devastation of the HIV in this country and the horror of that many of those who diagnosed with HIV experienced. Being ostracised, cut off from their communities of support. Denied treatment. Hospices were able to step into this arena with large amounts of funding from the USAID – PEFPAR, and Global Fund, despite some political challenges along the way.

Those initial grants managed through the Hospice Palliative Care Association essentially forced most Hospices, us, included, to develop wider care services and give expression to the principles of Palliative Care. Msunduzi Hospice was no different. With the changes in disease profile, we had to change and grow. These changes led to the amalgamation with the Edendale Hospice Association and a little later Rainbow Hospice Association to form Msunduzi Hospice. Extending services, growing, changing, evolving, developing.

The addition of TB to our range of diagnoses that we care for continued this trend of extension and development. Those were indeed heady days indeed. We adopted a model of Integrated Community Based Home Care that took into the wider communities of Pietermaritzburg. Took us into the homes of patients, assessing them, and allowing them to communicate their needs to us. Working with them and their families to plan the best care possible. Making sure that their physical conditions were not the only matters addressed. Asking them about how they were feeling, how they were coping, how their family were coping. How they were integrating their illness into their lives.

Illness is debilitating. Illness is always more than

physical and Palliative Care recognises this. Palliative Care begins to ask questions about how we are coping with our diagnosis. Palliative Care begins to assist the family members in how they are coping with the illness and potential death of their loved one. And while we no longer speak of terminal care, it is true, that due to the lack of resource, we tend to work primarily with those patients who are terminal. But what is it that we do? This question is still asked and forms an important aspect of our ongoing advocacy efforts. Indeed, we still need to educate the public about the work of Msunduzi Hospice. And so, I will try a little education myself this afternoon.

At its core, palliative care is about providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis. It helps improve quality of life for both the patient and the family. This is the main change; we have moved from speaking about terminal care to speaking about Quality of Life.

When diagnosed with a life threatening illness, time is precious. Most patients wish to die at home but frequently patients end up receiving aggressive, unnecessary, treatments in hospital. Accessing Palliative Care services early empowers the patient and family on how to navigate what comes next. Knowing that support is available in the comfort of your home relieves anxiety for many of our patients. Becoming comfortable with death. This support includes emotional, spiritual, social, and physical support. Making available pressure relieving devices, mobility, and bath aides. We also have trained wound care specialist nurses, and memory workers who capacitate children during difficult times.

Guiding us and providing structure are the Palliative Healthcare standards, the first edition going back to 1998. A set of standards against which we could be measured and held accountable. The first set of Palliative

Healthcare standards in the world and the only set in Africa that is recognised internationally by the International Society for Quality in Healthcare (ISQua). Msunduzi Hospice was not the first to be accredited by Cohsasa using these standards, but we are one of the longest continually accredited Hospices in the country. The current CEO was involved in the development of the 4th edition and will likely be involved in the review of these and the development of the 5th edition of the standards in 2024.

Another notable highlight as we reflect on our history and future, is funding from the KZN department of Health. Our first three year grant was received in April 2017. Making KwaZulu-Natal the first province in South Africa to make funding available for the provision of Palliative



Care services. This does need some clarification as other provinces do make funding available for Palliative care but in most cases, this is for the development of Palliative Care staff (training).

This brings us to where we are now. We survived Covid as an organisation. Extending our services to provide care to a small number of Covid patients and patients with the symptoms of Long Covid. Getting used to wearing masks, social distancing, and sanitizer. Our challenges have multiplied over the last three years and have placed us in a very precarious position with regards to funding and sustainability. The ability to continue to grow our services has been compromised and we are now in a position where we will be limiting our services. The assistance of all of you in overcoming the present challenges is required. Assistance in the form of cash, donations, ideas, and general support.

I would like to end by referencing two articles that have appeared in the Daily Maverick in the

last couple of weeks. The first titled “Initial Cancer claim volumes have spiked 631% over the past two years, analysis shows” (Daily Maverick 15 May 2023). Essentially that in the private sector (those with medical aid) the claims for initial diagnosis of cancer are up by over 600% in the last two years. This is for those with medical aid. I imagine that the number for those who are reliant on state health care may be higher. The second article I wish to reference is “HIV in graphs – latest figures confirm declining rates, but areas of concern remain.” (Daily Maverick 31 May 2023). Essentially, despite remaining challenges, the numbers are moving in the right direction.

What this means is that the field on which our Palliative Care services are provided is once again changing. As we look back, we must never lose sight of what lies ahead of us. Our task is more relevant now than ever before in our history as we work towards improving relationships with local oncologists and general practitioners so as to better provide much needed care to our patient and their families. Our work will slowly shift over the next few years back in the sphere of Non-Communicable Disease and our care will once again be available to those who are sent home to die. Their pain may be better controlled, but their emotional, social, familial, spiritual needs are not addressed, and that is where we will step in. Quality of Life. Where we have stepped in for the past 40 years and where we will step in for the next 40 years. Quality of Life is Palliative Care. Quality of Life is the work, duty, function, reason for existence of Msunduzi Hospice.

The second point to make in this newsletter is to highlight our very dire financial situation once again.

We will begin restricting admissions to our care programme with effect from the beginning of July as we simply do not have the capacity to provide care to as many people as previously.

This is only the first step in a process that may very well see us discharging up to half our current patient numbers in order to ensure that we continue to provide quality Palliative care. This is an epic tragedy, and the board and management of the organisation are deeply distressed by these circumstances.

We are simply unable to generate sufficient income to meet our need and this is resulting in

us having to cut our expenses quite dramatically.

I include here our updated Hospice Hero appeal and your support is urgently called for.

HOSPICE HEROES CAMPAIGN – HOSPICE CARE MATTERS

Help sustain quality Hospice and Palliative Care to 500 beneficiaries each month.

Become a Hospice Hero.

We are deeply grateful for the 27 Hospice Heroes who have supported the care of 129 beneficiaries during the first half of 2023 (end of June). These heroes have supported that care one or multiple beneficiaries and ensured that they receive the best possible Palliative care that we can provide.

There are still 2563 beneficiaries who need a Hero.

For each beneficiary that you support, that you empower us to care for, we are able to:

Provide access to medical care.

Provide access to pain relief and supportive care.

Provide spiritual and emotional support.

Provide access to specialised clinical equipment.

Our beneficiaries received 10031 visits and 43842 interventions through the generous support of the Hospice Heroes.

We call on you to continue your support of our services by donating R700.00 per month to the direct care of our beneficiaries. A section 18(A) receipt will be sent to you which will help reduce your tax liability (on request only). For businesses, details our SED and B-BBEE numbers can be provided on request. In addition, you will receive an electronic newsletter, an invitation to the AGM and a copy of the Annual Report after the AGM in May.

Deposits can be made into the following bank account – please use the reference – Hospice Hero + your name.

Nedbank Hayfields branch (134025)

Account number: 1340285053

Account name: Msunduzi Hospice Association

Please email a copy of the proof of payment so that we can follow up and obtain your details.

For more information, please contact Warren Oxford-Huggett (CEO) – warren@hospicekzn.co.za or Belinda Naidoo (Finance manager) – financemanager@hospicekzn.co.za

Contact details:

For membership inquiries and general reception, please contact Sonya on reception@hospicekzn.co.za

For additional information or queries please email hospice@hospicekzn.co.za

For care related matters, please contact Sheila on pmanager@hospicekzn.co.za

Please follow and like our Facebook page which will help you stay up to date on all the activities at Msunduzi Hospice:

<https://www.facebook.com/MsunduziHospice/>

Please visit our website: www.hospicekzn.co.za

Our YouTube channel has some video interviews that are worth watching:

<https://www.youtube.com/channel/UCd6aLZU5cisztYcHLL-ZpA>



R5 ENTRY

(033) 260-2800



Winter FAIR

SATURDAY, 29 JULY 2023 : 8AM TO 3PM :
HOSPICE HOUSE, 200 ZWARTKOP RD, PRESTBURY

FABULOUS BOOK HALL, FULLY STOCKED CHARITY SHOPS, WHITE ELEPHANT, STALL HOLDERS, PLANTS & SEEDLINGS +++



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