



April to June
2022

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From the desk of the CEO: Warren

While watching a rather good series on Showmax the other day, one of the characters quoted C S Lewis, 'Grief is like a long valley, a winding valley where any bend may reveal a totally new landscape.' (A grief observed, by CS Lewis).

At the moment the world is a sad place. A place of death and a place of grieving. I am told that there are millions of refugees fleeing the unjustifiable conflict in the Ukraine. Related to this conflict, the world teeters on the brink of unprecedented solidarity or unrest. The price of oil has skyrocketed and threatens to have a direct impact on our lives as individuals as well as the life of Msunduzi Hospice in providing Home-Based Care. The related increase in the cost of food will be with us shortly (if not already). Indeed, grief is all around.

Another quote from the same series is by the poet Rainer Maria Rilke:

*Let this darkness be a bell tower
and you the bell. As you ring,
what batters you becomes your strength.
Move back and forth into the change.
What is it like, such intensity of pain?
If the drink is bitter, turn yourself to wine.*

A call to embrace the pain and the struggle and the change. To learn from the grief, from the pain and to find meaning in our lives.

Indeed, in many ways this is the work of Palliative Care providers. The struggle of our patients to move from the point of diagnosis through the many avenues of their illness, to a place of meaning and value. Palliative care assists in this journey. The clinical interventions of pain and symptom control, the emotional support provided by social workers and counsellors, and the spiritual care provided by the team and our own spiritual guides has as its goal to help the patients live with as much

dignity as their illness affords until the moment of death. A dignified death. A death that has value. Followed by supportive care, bereavement counselling and emotional support to the family for as long as required afterwards.

We are more than just a death preparation service. We are here to help you live, to find meaning in your struggles and to find value in your life. We may not always succeed, but this is the work that we do. To encourage you to walk to the next bend in the journey, to see what lies beyond the rise, to be the bell and ring in your changes.

How do we do this? Time. The longer we are able to walk this journey with you the better. Please don't leave your request for assistance too late. Please don't consider Hospice as a death preparation service. We are here to help you live. Allow us the grace to journey with you. The clinical care will focus on your illness, controlling your pain and managing your symptoms. These may be major and have a great impact on your quality of life. Our emotional care will help you develop resilience in the face of your illness, the better to face your daily life. Unfortunately, our spiritual care is limited but we will encourage you contact either your minister of religion or someone who can provide this assistance. When we provide training on Palliative Care, we encourage our learners to reflect on Palliative Care as "...an approach that improves the quality of life of patients and their families' facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual."



Figure 1: Pieter speaks to Sr Brenda about his care.

The main goal of Palliative Care is “to improve quality of life. Quality of life is about an individual’s satisfaction with life - it looks at four areas of needs - physical, social, emotional (psychological) and spiritual (meaning). Quality of life changes as an individual’s experience and expectations change.”

*In this uncontainable night,
be the mystery at the crossroads of your
senses,
the meaning discovered there.
And if the world has ceased to hear you,
say to the silent earth: I flow.
To the rushing water, speak: I am.*

The poem by Rilke ends on a positive note. A note in which we speak our truth, our revelation, to the world, even if the world has ‘ceased to hear you.’ Allow Hospice to help you find your voice in your illness.

Warren Oxford-Huggett

Sheila, our Palliative Care Manager writes:

The provision of high-quality care during the final days and hours of life is an important component of palliative care. However palliative care should be initiated much earlier, as it is appropriate long before the final phase.

I often receive calls from family members or concerned friends requesting care for a loved one who is requiring assistance with pain and symptom control. After a long discussion the awkward moment arrives when the caller says, “can you come in a different car and don’t tell

the patient that you are from Hospice” we don’t want them to know they have cancer, we don’t want them to think they are dying, we don’t want them to give up hope”.

The goal of palliative care is patient comfort with the patient directing his/her care. Decisions should never be forced upon patients, including those of joining a palliative care programme. We endeavour to continue to educate the community around the stigma associated with Hospice care.

We cannot treat pain and physical symptoms without first establishing a safe and comfortable environment for the patient and family. Hence Msunduzi Hospice Association always requires the patient consent to commence care. The dying process takes *time*. Palliative care proves to be most effective when the care team has *time* to deliver it.

Unrelieved pain can cause or aggravate psychosocial problems as they are inter-related. These psychosocial problems cannot be treated well until the pain is relieved. The nurses need *time* to optimally manage pain and symptoms.

Pain may be aggravated by unrecognised or untreated psychosocial problems. Prescribed analgesia will not successfully relieve the patient’s pain until the psychosocial problems are addressed. Social workers and memory workers will need *time* to work with patients and their families to bring them to a place of acceptance.

Many people still feel that contacting hospice is about giving up hope. However, the truth is that people facing a life-threatening illness often redefine their hopes. Where a patient hoped for a cure, they may now hope to die pain free. For each person hope looks different. At Msunduzi Hospice Association our hope for patients and families is to be able to spend quality *time* and maintain hope during the remaining last days.

Sheila de Maroussem
(Palliative Care Manager)

A little bit about training

Pam Van Rooyen recently attended our Home-Based Care course. She had the following to say.



Figure 2: Participants at one of our HBC courses

"I would like to just share my thoughts on the Home-Based Care course I attended recently, run by the Msunduzi Hospice Association.

Our lecturer was Mama Winnie, as she became fondly known by us. A lady I became to admire greatly.

The course was conducted in English and in isiZulu, which helped everyone to understand what was been taught. We were taught many skills over the five days, both in theory and practically.

We also did a lot of group activity which I found very useful, as we exchanged different ideas. We also got to meet new people this way. Some who have now become friends. Mama Winnie taught and lectured us in a kind and safe environment. I would just like to add that as retired professional nurse, I certainly learnt a huge amount, on this course.

So, everyone out there wanting to do a Home-Based Care course, sign up for the next available course. You are never too old to learn new skills. Nor are you too old to refresh your skills.

Thank you, Msunduzi Hospice, for the running such a worthwhile course. Do not forget that you also get a certificate once you have completed the course. Such a bonus!"

Pam Van Rooyen
(Volunteer at Hospice)

Please make inquiries as to the training available from Msunduzi Hospice. You can speak to Sheila on 0607173949 or email her on pcmanager@hospicekzn.co.za

Memory work: Ben and Letitia

The Memory work programme at Hospice targets children under the age of 18 years whose loved ones are sick or have died as a result of a life threatening illness. As we have just passed the two year anniversary of the COVID pandemic (27.03.2020) we reflect on a time which was very disruptive for most organisations in the business of providing quality palliative care to children. The healing sessions which are held quarterly (during the school holidays) was discontinued during 2020. During 2021 only two of the groups were held (Easter and December).

The effect thereof filtered down to entire families who were already trying to adjust to the daily demands of the protocols implemented to safeguard our communities. However, the programme has made us realise the importance of children having a platform to voice their fears, feelings, to identify with other children and to just be children.

We are currently in the process of conducting our first healing session group on the 29th and 30th of March 2022. We hope to have 16 children on each of the days where the PEPFAR deliverables (including information sharing on Gender Based Violence) and treatment adherence will be part of the programme. I would like to share a story of a child who has benefitted from the Memory work programme.

A Memory work referral was made in February 2021, for Odette (7years) who resides with her grandmother in Snathing.

Odette has 1 sister and three brothers as well as an aunt and they all stay together. Odette was on HAART (Highly Aggressive Anti-Retroviral Treatment) and was very sick on referral. Both her parents are deceased, she does not have a birth certificate and therefore no child support grant can be accessed. The Care Team worked together to monitor the child's condition, support the family, and assisted with the application of a birth document.

Medication (ARV's), adherence to treatment and the importance of follow up visits to the Clinic were encouraged by the nurse. The Memory worker educated the child on the "hand of safety" good morning and good night medication and the importance thereof. The social worker facilitated the birth document application. The child also could not attend

creche due to her ill health. Her health has subsequently improved, she is coping better with her illness, and she started Grade 1. She attended the Zoe Life groups, family members support the children appropriately and she is more aware of her family history.

Report compiled by: Bernard Sefadi and Letitia Marais



Figure 3 celebrating valentine's day

Important notice: AGM

The AGM of the Msunduzi Hospice Association will take place on 26 May at 15:00 at Msunduzi Hospice Association (200 Zwartkop Road).

In order to plan for this AGM and to adhere to the required Covid protocols, please make sure you let us know if you will be attending. There will be limited seating available, and masks will need to be worn while indoors.

We anticipate some vacancies on our board, and we would like to encourage people to apply to fill these vacancies. Applications (CV's and ID documents and professional registrations) must be received by the CEO on or before 30 April 2022.

Events and functions: 2022

Please keep up to date on these events by following our Facebook page or requesting Tanya to place you on our mailing list (fundraiser@hospicekzn.co.za).

Further, we humbly call upon you to share our advertising of the planned events as widely as possible within your own set of contacts and networks.

Tanya Roux (Marketing and events coordinator).

Cohsasa survey

Our next assessment by our independent external assessors will take place at the beginning of June. The Council for Health Service Accreditation will be conducting an assessment of our operations.

We have been preparing ourselves for this assessment and we trust that our preparations will not be in vain.

Contact details:

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

To join our e-mailing list or for more information on our events please contact Tanya on fundraiser@hospicekzn.co.za

For care related matters, please contact Sheila on pcmanager@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/>

Our website has additional information on the services available at Msunduzi Hospice and how to access them. There is a Hospice Blog that is updated occasionally:

www.hospicekzn.co.za

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

<https://www.youtube.com/channel/UCd6aLZU5ciszytchLL-ZpA>