

# CANCER ALLIANCE: PALLIATIVE CARE POLICY

## SECTION 4 – STORIES OF HOPE, CARE AND SURVIVAL

### **KNOW YOUR RIGHTS: ALL CANCER PATIENTS, IRRESPECTIVE OF WHERE YOU LIVE, HAVE A RIGHT TO PALLIATIVE CARE, STARTING AT THE TIME OF DIAGNOSIS.**

Palliative care is explicitly recognised under the human right to health. It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals. – World Health Organisation<sup>1</sup>

### HOSPICE WEDDING MARKS NEW BEGINNING

Cancer patient Zanelle Mphikwa found out that hospice care isn't necessarily about endings when she got her new beginning, marrying her soulmate and love of her life Ilze de Brandt at the Stepping Stone Hospice.

Just six months into their relationship, Zanelle was diagnosed with urethral and bladder cancer, and for the next four years the couple fought the disease together – from radiation to chemotherapy, to remission and out of remission, and then to the hospice.

Ilze had hardly left Zanelle's side since that shocking diagnosis day in 2012, and when the couple decided to marry, a wonderful group of people worked to make it the best day possible.

That group included their amazing friends, calling themselves the **7 Wonders**, who worked with hospice staff, management and the **National Paramedical Services** to arrange a storybook wedding in the hospice gardens.

"I just knew she was the one," said Zanelle of their first meeting in 2011 when they worked together at the **Broadreach Corporation**.<sup>2</sup>

## HOSPICE IS A HOME FROM HOME

When Lee Govender first visited the Chatsworth Hospice after radiation and chemotherapy had left her feeling like giving up was the only option, she says she was met with love, warmth and compassion that she will never forget.

After signing up for extra support, that day was the first during her illness that she no longer feared her cancer. "It was the first time I could let go of the fear of both the cancer and my treatment, because of the amazing reassurance I received there," she recalls.

The hospice became a home away from home, where she looked forward to visiting weekly for her check-ups and a day filled with activities.

"There is so much for us to do and experience, from massage therapy, to seeing a spiritual leader, and even a hairstylist. It helped me so much. I cannot emphasise that enough," says Lee.

Now she's confident when she says hospice is not only about death, as so many believe.

"It's very much about living too." <sup>3</sup>

## COMMUNITY OF CARE

Samekelisiwe Mkhonza was her parent's second "bundle of joy" to arrive, but their excitement soon turned to distress when, two years later, the most difficult two years of their life would begin.

Sammy, as she was affectionately known, had just turned three when she was diagnosed with a kidney tumour, and her parents got the news that her kidney would have to be removed to prevent the threat of the cancer spreading to other parts of her little body.

Chemotherapy followed the surgery, and so began the long days of countless drips, injections and blood tests at Unitas Hospital. Even worse, because her parents lived far from the hospital, staying at their daughter's side meant sleeping in their car.

Just as they proved to be Sammy's source of strength, so too did the **Childhood Cancer Foundation of South Africa (CHOC)** for the couple. They soon provided a place for them to stay, removing the terrible stress of not having "a place to lay their heads".

But Sammy will also never forget the memorable hospital visits, gifts and annual Christmas parties hosted by **CHOC**.

"I will be forever grateful to the **CHOC** for what they did for us in our time of need," she says.

## CHALLENGE LIKE NO OTHER

Shaun Thornhill knows the true meaning of saying that cancer is a challenge like no other; he watched his one-year-old daughter Shaye scream in pain as she underwent five operations in three months following a cancer diagnosis.

"In my mind, I will forever feel dread at the day the paediatric surgeon sat my wife and I down to explain that Shaye would have to be transferred to Red Cross Children's Hospital to have a tumour removed from below her coccyx."

The operations that followed, along with the chemotherapy when his daughter screamed at the many needles "that would hurt her little body", left him feeling helpless and broken.

"You never get over the helplessness. It really felt like we were out of control, never knowing when it would be over ... if it would ever be over," he recalls.

The **Childhood Cancer Foundation of South Africa (CHOC)** offered them the lifeline they craved, when a social worker assigned to them proved an integral part of their journey.

"Their staff and volunteers were always so warm and caring at the ward and with follow-ups, and just seemed to make everything lighter."

The couple are both now themselves **CHOC** volunteers, paying forward the support they received to others going through similar experiences.

## LONG ROAD TO HEALTH

She was just 12 when she was first diagnosed with Chronic Myelogenous Leukaemia.

Then, following 18 months in remission, Zukisa Mukwevho relapsed and the diagnosis was worse - Chronic Myelogenous Leukaemia and Acute Lymphocytic Leukaemia.

"I was devastated. I thought that world of words like bone marrow, lumbar puncture, chemotherapy, prescriptions and pills was behind me. I had missed school, left my family and friends, and now it was back," she recalls.

It was during that initial 18 months of treatment that Zukisa first learnt the huge value of the support offered by the **Childhood Cancer Foundation of South Africa (CHOC)** to children with cancer, and their families.

Her story had a fortunate ending, when she was included in a trial in Johannesburg for a new drug, which literally changed her future.

"Today I am 35 years old and have been blessed to experience motherhood, something I never imagined when I was diagnosed," says Zukisa.

She knows she is living proof that childhood cancer can be beaten, and needn't be a death sentence, and now works for **CHOC** to provide solace to similarly affected patients and their parents.

"I work to keep hope alive," Zukisa says.

#### WHERE TO FIND PALLIATIVE CARE

The Hospice palliative Care Association of South Africa (HPCA) has information about where to find a hospice, and how to ask for palliative care at <https://hpca.co.za/>

The Childhood Cancer Foundation (CHOC) has support programmes and advice. Find out more at <http://choc.org.za/>

Paedspal, the Paediatric Palliative Care organisation is a great resource for support for babies. They are at <http://paedspal.org.za/>

**REFERENCES:**

1. World Health Organisation. Palliative care. Retrieved on August 8, 2018, from <http://bit.ly/PalCareFacts>
2. Hospice Palliative Care Association of South Africa. Storybook Wedding at Stepping Stone Hospice. Retrieved on August 9, 2018, from <http://bit.ly/StorybookWedding>
3. Hospice Palliative Care Association of South Africa. More than just a hospice, it's a home. Retrieved on August 9, 2018, from <http://bit.ly/HospiceHome>

## SOCIAL MEDIA

1. **#PalliativeCare** means that there is support for your time of need  
**#LetsTalkAboutCancer #RightToHealth** <http://bit.ly/PalCareToolkit>
2. **#PalliativeCare** is about love, warmth and compassion as well as psychosocial support  
**#LetsTalkAboutCancer #RightToHealth**  
<http://bit.ly/PalCareToolkit>
3. **#PalliativeCare** keeps hope alive **#LetsTalkAboutCancer #RightToHealth**  
<http://bit.ly/PalCareToolkit>
4. **#PalliativeCare** provides support for patients and their families from the time of diagnosis to end of life if necessary  
**#LetsTalkAboutCancer #RightToHealth**  
<http://bit.ly/PalCareToolkit>
5. **#PalliativeCare** means having a support team that can provide the answers you need  
**#LetsTalkAboutCancer #RightToHealth** <http://bit.ly/PalCareToolkit>
6. Your **#PalliativeCare** team is a source of strength and advice  
**#LetsTalkAboutCancer #RightToHealth** <http://bit.ly/PalCareToolkit>