

218 Kemston Ave, Benoni P.O. Box 17160, Benoni West, 1503

Telephone: 011 4221531/2 • Fax: 011 421-4785 • Registration Number 001-392NPO Website: www.hospiceeastrand.co.za email: info@hospiceeastrand.co.za

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HOSPICE EAST RAND SAME TODAY, YESTERDAY AND TOMORROW!

"HOPE IS SOMETHING WE DO WITH OTHERS. HOPE IS TOO IMPORTANT - IT'S EFFECTS ON BODY AND SOUL TOO SIGNIFICANT - TO BE LEFT TO INDIVIDUALS ALONE. HOPE MUST BE THE RESPONSIBILITY OF THE COMMUNITY "

-Kaethe Weingarten-

HOSPICE TODAY - A STORY OF HOPE

Isn't it often the case in life that the smallest of incidents be it a word, a gesture, a chance meeting can be a catalyst that can only properly be appreciated on hindsight!

I arrive at Lynette's current place of abode which is a section of the residential care home Shady Pines. It's a romantic name and appropriate as it is situated in the rural area known as Benoni Agricultural Holdings. One certainly gets the impression of being out in the country with the expansive green views around.



Lynette is standing waiting to greet me at the top of the steps-she is the picture of elegance, perfectly groomed with a warm smile disarming any sense of shyness on my part! She puts me at my ease! I have to admit she is a far cry from the image I had created in my head given her diagnoses and stage of disease! If ever there is an example of LIVING graciously with cancer Lynette is one such lady!

Having said that, there is a great deal that Lynette has to overcome to present herself as she does. Undoubtedly these days, the greatest being the problem of her pain.

However a glimpse into the life that I was privy to hear about from Lynette reveals an overwhelming sense of the phrase "against all odds"! That very theme assailed from the moment of her birth! She was diagnosed with an atrial septal defect (hole in the heart) which required immediate surgery. Lynette was born to a young single Mom who had chosen to give up her baby for adoption. Lynette says that the proposed adoptive parents were informed about her heart condition and given the choice by Social Services to withdraw from the agreement to adopt. They declined that option. Lynette's operation was performed and was a complete success. Lynette's new family comprised of a Mom and Dad and a brother David who had been adopted by the family three years previously.

Asked if in the ensuing years she had ever attempted to find her biological mother she says she did but was discouraged by the efforts of the Social Services at that time and decided not to persue that exploration any more.

During her growing up years the family lived on the East Rand. Lynette and David were schooled in Kempton Park. She and David had a good relationship. Lynette recalls a happy family life.

It therefore came as a great shock, after Lynette's matric year to discover that her parents were to be divorced! This was a very painful experience for Lynette! The love and safety of the home that she had known seemed over night to vanish into mid-air. She was devastated! Lynette then entered the job market and worked as a saleslady before subsequently working in a hardware store for a total of 7 years. Internal staff conflict forced Lynette to resign . The years that followed saw Lynette struggling with severe depression, resorting to maladaptive ways of coping and resulting in several admissions to various psychiatric institutions. She was diagnosed with bi-polar disorder. Lynette describes a life that was chaotic and at times the desperation so great that she, on more than one occasion tried to take her own life! The relationship with brother David deteriorated and her Mom developed a dependency on alcohol. Her relationship with her father was emotionally as well as physically distant .He had moved to Port Elizabeth.

When asked about other relationships in her life Lynette went to a drawer nearby and took out some framed photos coated in dust indicating it had been some time since viewing these photos! The photo that put a smile on Lynette's face was that of Jean V who was a keen motorcyclist who often rode with Lynette as a pillion passenger! Asked whether she ever took over the driver's seat she said "no "she was more than happy to take a back seat!

Some years after this Lynette and Mom moved to Mackenzie Park . It was soon after that , that tragedy struck again . Lynette discovered a lump on her right breast . After some inappropriate medical decisions she finally landed under the care of a surgeon who performed a right mastectomy followed not long after with a left mastectomy . She was referred subsequently to the oncology unit at the Glynwood Hospital where she was told that her cancer was a particularly aggressive type but radiation and chemotherapy was strongly advised. At this stage the cancer had spread to the gallbladder. A cholecystectomy was performed. Lynette bravely went through all the treatment until the day she was told by the oncologist that her disease was no longer responding to treatment and in fact the cancer had further spread to the liver. Her response to that was one of shock and reactive anger but countered by the relief that she would no longer have to go through treatment.

Asking Lynette what this whole experience had taught her? Her reply was ..."To trust no one! "

It was at this time that Lynette remembered the lady called Sheena who had come to the ward at the Glynwood to see her but as the screens were around Lynette's bed Sheena just popped her head around the curtain handing over a business card saying "if at anytime you need help give me a ring "!

That card was indeed... the catalyst!

Sheena represents a cancer support group now known as 'wings of hope." Lynette duly phoned Sheena and attended a few of the group meetings. When Lynette stopped attending ... Sheena paid a visit to Lynette's home in Mackenzie Park and discovered that she and Mom were simply not coping! Now Sheena, being the owner of Shady Pines, was in the fortunate position of being able to extend an invitation to Lynette and her Mom to come and live at Shady Pines. There was no hesitation in accepting that invitation ...'it was like a life line 'Lynette said .

Sheena realised quickly that Lynette needed help with her symptoms of pain, nausea vomiting etc and with medication. With Lynette's consent she requested the services of Hospice East Rand! What a thrill

it was for Sheena, when Sister Marja appeared as the Community Sister allocated to attend to Lynette. Marja had been the Hospice Sister who had attended to her Dad on the very same property many years previously!

And so the journey with Hospice East Rand began and continues to today. Some 2 years later the routine is such... Sister Marja visits every Friday and is in 24 hour cellphone contact, Dr Jenni the Hospice doctor sees Lynette once per month and she in turn is available 24 hrs for Sister Marja.

Lynette's condition is stable but now and again serious complications arise from the disease process! Her abdominal distention due to advanced liver involvement is a source of huge discomfort. She is adamant she will not go back into hospital regardless of circumstance. Her support system is geared for that! This medical support structure, in its consistency and reliability, is what affords Lynette a peace of mind that she has rarely experienced in her recent life. Testimony to that fact is that 2 months ago Lynette's Mom suddenly and tragically passed away in her sleep. Lynette was to discover her in the morning when she went to wake her up! Their relationship over the past years had been an extremely supportive one so yet again Lynette faced trauma on a major scale! It is testimony to her support system that she has been able to work through that grief.

Additional to the aforementioned support is the ongoing amazing support of Sheena in so many aspects! Also a gentleman friend named Bill has become a great source of companionship and encouragement! Lynette described him as her soulmate!

A year ago with the support of these friends Lynette was able to take a flight to Port Elizabeth to reconnect with her Dad and celebrate her birthday with him! They are now in regular conversation! David is also in contact with Lynette. Both contacts mean a great deal to Lynette.

Asked about a spiritual connection ...Lynette said in her own words "God and I have a special relationship!"

Finally asking Lynette to comment about the 'trust' comment eluded to in the conversation, she says Hospice East Rand, Sister Marja, Dr Jenni, Shady Pines proprietor Sheena and others have totally restored her loss of trust. The support of her family has also significantly contributed to that.



Lynette and her companion GRIETJIE,



constant a very special

and much loved miniature daschund.

HOSPICE YESTERDAY

ANNATJIE's STORY

Annatjie lives in her own little cottage in Rynpark .She is in her 89th year now and though still capable of looking after herself she admits that some days it is more difficult than others. She relishes visitors and it tells in her countenance ...her sad face begins to relax ,her colour no longer grey -she comes back to life as it were with a flush of pink in her cheeks and a smile lights up her whole face !

It is now 12 years that Annatjie has been without Riaan, her husband, life companion and soul mate! They did not have any offspring but they certainly had each other!

She is so eager to talk of the last year of Riaan's life and without prompting she says she will never forget HOSPICE EAST RAND!

When asked what word would encapsulate her experience she thinks for not more than a second and says ...KINDNESS quickly following up with the words VERSORGING and OMGEE! She further goes on to describe the relief of having someone to share the responsibility of looking after Riaan and helping him with his pain as well as attending to the massive surgical wound that had been a complication of the cancer. These two factors on their own had literally been lifesaving!

At one stage during the journey with HOSPICE Riaan had recovered sufficiently to be able to attend the daycare on a Wednesday . In Annatije's words "Riaan and I lived for Wednesdays!"

Riaan had a great sense of humour and had an amazing repertoire of jokes! Annatije recalls the banter between Riaan and the Hospice Sister! She recalls also the time the Sister presented Riaan with a plant for his birthday saying "you've earned this cause you're 'bloomin' good!"

As Annatjie reviews her own life, struggling with a major life decision she must make, she feels the loneliness of that space, but despite that she is extremely grateful for the few relatives who are very

concerned for her welfare!

She dips into her bible and brings out a note, words of encouragement from the Hospice Sister, written to her in these difficult times and now equally pertinent for these present days! She smiles!

This story has an addendum! Since the above was written Annatjie was transferred from her little cottage to the frail care at Rynpark. Annatjie is adjusting very well to her new environment! She is feeling a lot safer and being freed of the responsibility of caring for herself she admits, is a tremendous relief .Of course she misses the

familiarity of her old 'space 'but she has surrounded herself with wall to wall photos and proudly shows me a beautifully illustrated biographical story of her life created for her by her 'grandchild '. A change of environment maybe but Annatjie's indomitable spirit lives on!

ELSA'S STORY

"You read the letters to Basil because I could not bring myself to do that ...it was too hard, too painful! "

These were the words remembered and shared with the HOSPICE EAST RAND Sister who indeed some 18 yrs. previously had had the privileged task of reading letters from children in Australia who wanted to say farewell to their Dad!

Aunty Elsa in the years since has become everyone's "Aunty". How else can you address a Grande Dame of stature that equals her 95 yrs.

Spending time with her in recent days was awe-inspiring to say the least! Her mental acuity and all other abilities as a nonagenarian she attributes to her Lord Jesus! Aunty Elsa has espoused the Christian faith and been a Christ follower for as long as she can remember! No one coming into her presence can help being captured by the vitality of that personal faith - it just exudes from every pore in her body!

Her memories of the experience with HOSPICE EAST RAND as an organisation are very positive! Her daughter recalled the feedback relayed from her Mom following each of the Nursing Sister's visits! Having no interface with the Sister the feedback was important to her, even more so, as she herself was a qualified Nursing Sister. She shared what a relief it was to know and witness her Mom's confidence in the Sister and the services of HOSPICE EAST RAND and as she described Mom gained strength from each visit .

Aunty Elsa had tremendous support from her church community but still she said she valued greatly the time spent by the Hospice Sister who never seemed to be in a hurry! She and Basil appreciated the words of advice, as well as the physical and emotional support.

A shared experience as exists with the Hospice / family interplay often transcends the limitations of that interaction and becomes the foundation of a symbiotic relationship that becomes a lifelong privilege. That has certainly been the experience of this Hospice Sister.





MARY'S STORY

I asked Mary the question.....

What difference did it make having HOSPICE EAST RAND involved in the care of your husband Brian when he was ill with cancer? (Brian died 3 August 2004.)

Mary wrote this response:

"We were heading into the unknown – a place of fear, filled with anxiety and heartache; a feeling of helplessness, a loss of control. My husband Brian's cancer had finally been diagnosed as terminal.

Responding to a suggestion by the hospital to get in touch with HOSPICE EAST RAND. We contacted them and we were visited by an amazing Hospice Nursing Sister. Sister S' quiet, gentle, kind, caring and efficient ways put us at ease from her first visit. She obviously couldn't take away the terminal illness that had struck my husband, but she was able to monitor Brian's condition, administer his meds, and liaise with his doctor. Brian was treated with dignity and respect and Sister S definitely brought a sense of peace to our home. We felt that we could face my husband's last few weeks, with her walking every step of the way with us. Brian just loved Sister S and because of her, he was able to stay in his own home until he passed away. That was his last wish. HOSPICE EAST RAND had sent us a guardian angel, and our whole family will never forget Sister S."

Mary G. Zanker

Stories compiled by Sister S, former Hospice East Rand community Sister.

NO CANCER IMMUNITY FOR HOSPICE STAFF!



I am sure, Dear Reader, that the above statement is no surprise to you unless of course there's a sneaky reward system going on in your head, trying to gain credence in a thought process influenced by an 'effort / reward system 'which is all too familiar in our everyday dealings! Think of the Amazing Race ...doesn't it reward with immunity!!

Hospice is a microcosm of our greater community and in S A at the moment statistics, according to CANSA, reveal a staggering prevalence rate of 1: 4. That figure includes all Cancer types, all ages, and all ethnic groups!

Working in a small community whose focus is predominately, though not exclusively cancer orientated, that prevalence rate can feel very real indeed!

It was with that background in mind certain questions were posed to staff members currently in the employ of hospice who have had their own experience with cancer.

The group comprised of 7 females at various stages of the journey. Some in remission for 10 years, some more recent while others currently undergoing active treatment.

Questions were aimed at targeting such information as

- -The influence of the nature of the environment
- Personal narratives
- Learning experiences that may be beneficial to pass on

These were some of the responses

Lucille. "Initial shock, feeling of disconnect like being in a movie. No difference being in hospice environment, support of colleagues important, added difficulty.....emotional shut down due to brain pathology complicating communication. A significant spiritual journey."

Rika. "Shock, surgery next day. Came to get a wig from Hospice, became an instant day care patient, completed the caregiver's course, then subsequently and currently volunteer staff member. Hospice has become a major part of my life. "

Maureen. "Currently in treatment! Hospice environment not a negative, never considered not returning to work. Support structure at Hospice from fellow survivors - vital commodity for keeping positive, never alone."

Brenda. "Routine exam for arthritis. Shock! Leukaemia diagnosed. Recently widowed, children out of the country, resilient and positive. Grateful for good medical aid. Laughter good therapy! A resoluteness about "getting on with what it takes "Hospice connection not an issue."

L.aura. "Not part of Hospice at the time, good colleague support in another N G O environment, people didn't know how to react, good treatment in non-private facility, increased awareness of suffering and need to advocate health education."

Carol. "Self-aware.....persued diagnosis. Need for understanding, advocates fearless questioning, not disadvantaged by working in Hospice environment, colleague and management support critical, positive mind-set vital."

Marge. "Currently on treatment, violently ill swept up in avalanche of symptoms, Hospice caregiving experience helps perspective, as with others on treatment esp. witnessing young lives, everyone spoke around in whispers, loss of hair difficult, keep focused on Drs communication, not others."

The exercise was both, illuminating and privileged! Being privy to these stories.....a special connecting of sorts!

The conclusion

An effort /reward system had no existence and the Hospice environment was never seen as a threat or somewhere not to return to, on the contrary being part of the hospice community was upholding and sustaining.

No two personal narratives were alike, nor in the least bit similar.

The unanimous conclusion was that being given a Cancer diagnoses was/is a life changing experience!

Crucial to 'good recovery' is a sound support system.

It was interesting that in spite of sharing the same environment, the actual detail of each personal experience was being heard for the first time, highlighting the need for one's story to be heard in depth.

It may be, Dear Reader, that you are, or may in the future become aware of someone undergoing a similar journey but not privy to a support system such as has been identified.

This is where HOSPICE EAST RAND can offer help, uniquely matching a need to a resource whether it be physical, emotional or psychosocial.

HOSPICE TOMORROW

What is HOSPICE and who do we care for?

Contrary to a widespread belief Hospice is not about **DYING** ..it is that... but it is very much MORE than thatit is about **LIVING**, it is about living the best life one can, within the limitations of a life threatening disease! **HOSPICE EAST RAND** offers appropriate care regardless of stage of disease.

Patients with the following diagnoses are eligible for care:

Cancer, HIV/AIDS, late stage Emphysema, Motor Neurone Disease, Liver and Renal failure.

The essence of our care is based on **IMPROVING** quality of life using a **HOLISTIC** approach aiming to meet the Medical, Nursing, Emotional, Social and Spiritual needs of the patient and family.

How do we do that?

We do that by practising **PALLIATIVE** care! This specialised medical care comprises a team of medical doctors and palliatively trained nurses as well as social workers and trained counsellors. HOSPICE EAST RAND offers **TOTAL** active care of patients whose disease is no longer responsive to curative treatment. The focus is on providing relief of symptoms such as pain, nausea, shortness of breath, fatigue, constipation, insomnia and depression. Emotional and psychosocial support is offered to patient and family members alike .

Where do we do that?

The major part of Hospice care takes place in the comfort of the patients own **HOME.**

When should we contact HOSPICE?

Hospice can accommodate patients at ANY stage. It is important to emphasize that effective symptom management can greatly enhance quality of life. Emotional support for patient as well as family can ease the burden of responsibility.

How does one access the services of HOSPICE EAST RAND?

Access to services is initiated by a phone call to the reception at **HOSPICE EAST RAND.** The contact no is **011 422 1531**. The only stipulation is ... in the case of a relative/friend making the contact ...the patient must give his/her consent for the request where possible .

It is not necessary to be referred by a Doctor or Specialist.

Hospice East Rand is a registered accredited hospice for the entire East Rand. It is a non-governmental organisation dependent on the generosity of donors and fund raising ventures

IF YOU WOULD LIKE TO SUPPORT THE WORK OF HOSPICE . THE DETAILS ARE AS FOLLOWS:

FOR EFT PAYMENTS

HOSPICE FAST RAND

ABSA -BENONI

ACC NO 710465673

RRANCH CODE 630 747

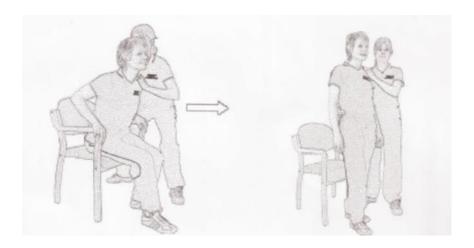
PLEASE USE THIS REFERENCE ON YOUR DEPOSIT - "YOUR NAME AND HT"

OR HAND DELIVER TO 218 KEMSTON AVENUE. BENONI with CHEQUE OR CASH PAYMENT

Thank you for caring

HELPFUL HINTS FOR HOME NURSING

Feature 1. SITTING TO STANDING



- Move the bottom forward in the chair
- Place feet apart , one slightly in front of the other
- Place hands on the arms of the chair
- Ask the person to look forward
- Ask person to lean forward so their head is over their toes
- Carer places left hand on shoulder, right hand centre of back
- A command of 'ready steady go'
- Person is instructed to push with their hands and
- STAND up on the command of stand!

If a walking aid is used this should be placed for access

N.B not recommended!!!

