Abundant Life Palliative Care

Victoria Hospital

Progress Report 2011

Date: 07 September 2011

By: Dr Clint Cupido

Introduction

Abundant Life Palliative Care Victoria Hospital (AL) has been in existence for over 2 years now and we have cared for well over 200 patients since our inception. The program has evolved through a number of phases and I will briefly explain the phases and reasons for change. This report must be read in conjunction with previous papers relating to AL.

In Brief:

Dr Lindi Van Niekerk in 2008 had a patient aged 26 year old who died from Kidney Failure and she wondered how we could have treated him differently. In 2009 we had a presentation by a visiting doctor from the UK who presented the Gold Standard Approach to palliative Care in the UK. This sparked Dr van Niekerk's dream of AL. She then did some research as to our current palliative care for organ failure which was minimal or non-existent. She presented her findings and proposal to Victoria Hospital Administration but was told it was not possible.

Dr van Niekerk approached Dr Cupido and together they changed the proposal to do a trial of AL with funding from Rotary Claremont. The Trial was done successfully and when presented to the Hospital Administration they were impressed and agreed to assist in the future of AL.

Meetings held between the initial supporters and funders included Victoria Hospital Staff, St Luke's Hospice, Living Hope Hospice, Hospice Palliative Care Association South Africa (HPCA) . AL continued the program with the Doctors, Physiotherapy, Occupational Therapy, Social Worker and Spiritual counselor as best we could.

In 2010 AL received funding from HPCA (USAID) to specifically fund a Palliative Care Professional Nurse. We appointed Elizabeth Pitout into this position and she enrolled in the Palliative Care Nursing course which she completes October 2011. Since her appointment she has not had an increase in salary, but there has been substantial increase in work load as she has done a remarkable job of promoting palliative care in Victoria Hospital.

In 2010 Sr Pitout had a year which was extremely difficult in that she was new to palliative care and palliative care was new to Victoria. Working alone and initially seen as someone creating more work and interfering in the usual hospital work, she struggled to find her feet in the hospital. I spent many a week convincing her that she was the person for the job. That all new programs are never greeted with open arms in an old institution and that it is not the staff but the patients that are important. In 2010 we continued the original program structure however as we entered the new year we reviewed and restructured.

January 2011 we had the pleasure of having Dr Roslyn Doyle an Australian GP with an interest in palliative care volunteered 6 months of her time to AL. This added a new dimension to our program and restructuring was inevitable. Again for Sr Pitout this was not an easy 6 months as we had someone with a different approach and different background. We adapted and grew in a number of ways. We started home visits and we saw patients and families on a daily basis as Dr Doyle was available. We no longer required the 3 week group program we started with. The group sessions are now held twice a month with a different focus. It is now a support group for old and new patients as well as family members of lost loved ones.

As we grew more work has been generated and we employed Fatima Gallow as our resource development officer. She is an assistant to Dr Cupido and Sr Pitout. She liaises with our patients and has been raising funds for us as well.

Today we are having over 70 active patients and Dr Doyle has left us.

Sr Pitout is still working 5 hours per day and doing many house visits. She works many hours overtime and uses her own vehicle to do home visits. Her commitment to our patients and their families is commendable.

Dr Cupido has not manage to devout any more time to AL as his Department of Medicine is also growing and requires all his attention.

Fatima Gallow has been consumed by the patient work load and has not been able to make progress on the fund raising front.

Our group sessions are catered for by our own Star Fish Foundation Santa Moron who has been with us since her friend was a patient on the program in 2010.

Joy Hunter is a psychologist with a special interest in palliative care and she is also available at our sessions.

Our Spiritual counselor has not been able to make it for 2011 and our counselor from Hope House has not been available for the past few months.

Fund Raising:

Main funding from HPCA R6000 per month is for salary

Once off Tsitsikama Water R4000 for T-shirts

Viking Fishing R7500

Water Sales R200 per month

Dr Cupido R150 per month

Dr Luker R111.11 per month

Dr Pema R150 per month

Once off Dreyer Stevens R5 800

Donations Dr Sassman R2000

T-Shirt sales R2500

Once Off Francis R609

Once Off Funeral Collection R1200

Wheel chairs R1500 donations 6+4+2 =12 R18000

Dr Doyle R30 000 X 6 = R180 000

Once off R221 600

First year Rotary R30000

USAID HPCA R72 000 2010 and for 2011 as R6000 monthly

Doctors monthly donations R500 and growing

Community involvement:

Since August 2011 our patients have taken it upon themselves to ensure that AL does not cease to exist as they have not seen any progress from Department of Health or the Hospital to start funding AL. Patients and families have experienced AL first hand and have also had previous experiences with the Health Department. Their actions speak for themselves.

The Dreyer and Stevens Family organized a choral evening in Seawinds and raised R5800.

The Sylvester Family raised money and bought 3 wheelchairs for AL.

The Francis Family held a collection at their dad's funeral for AL.

This is fast becoming the communities' program and that is exactly what Victoria Hospital is the Communities Hospital.

Now the Karriem family is hosting an Event on the 8th October 2011 at the Bega Road Hall in aid of AL. Note that none of the employees of Victoria have been involved in these fundraising events. AL has merely been invited to attend, say a few words as the beneficiary.

We are also being asked to attend a Radio Show for an interview to raise further awareness of our work. I am sure there will be another newspaper article.

Research:

AL has presented at the South African Palliative Care Conference in 2009 which lead to our Funding from HPCA.

AL presented at the International Primary Palliative Research Forum in 2010.

A paper has been written is currently with Prof. Richard Harding of the Kings College London Palliative Care Group for editing for publication.

Dr Cupido has been invited to spend 2 weeks at the Kings College London Palliative Care Program in October.

Hospice Palliative Care Association of SA has been singing the praises of AL and so has people like Kathy Grammer. The evidence as to the benefits for better quality of care and cost effectiveness, better management of beds for non-communicable diseases and organ failure are irrefutable.

AL FUTURE

With the above information I see the future of AL as a bright one.

Government is **not** going to be providing more Kidney Transplants or more Dialysis, or More Heart Transplants, more home oxygen, more nursing homes, more hospital beds and this is making a huge difference to Quality of care and improved Health Care.

Of huge concern is the international recognition of our work and yet our own hospital is not yet convinced of the impact to put funding on the table for AL.

The Department of Health Kathy Grammer in January 2011 indicated that this was a superb program that had her full support and to date I have not had the opportunity to present at a GSA meeting or any health department meeting. She has also said to Victoria Hospital that this should be prioritized.

The Community is now showing interest and is pushing for media exposure and the fund raising efforts are going to be exposed in due course.

I have had previous issues with media exposure and I am not interested in getting into any further enquiries. I can promise you that I have not been asking patients to do this and I am only to proud to have a program that has generated such respect for Victoria Hospital.

This is not the only program at Victoria that the community is proud of. We should really embrace this opportunity but I need to ensure that this is done by the book.

Where is the Board Role here?

Does the Hospital and The Department of Health want to be seen as not supportive of this program?

To say that you support us when having no financial input, no staffing input and only providing the facility that we essentially are using but providing all our own equipment. This will not look good in the media. Not taking Part in the initial media events that are going to happen would not be appropriate from my perspective.

I am committed to Victoria and see a long future here for me.

I am thus asking for urgent discussion around this.

This is Victoria Hospital's opportunity to get the Community on our side to assist with AL, Paediatric Project, Emergency Department, Cardiac Rehabilitation, Better Transport Routes, A prayer Room or Quiet Area, our CT Scanner.

AL has quietly been doing our work and we need to now start reaping the benefits.

Not to forget:

Lindi Van Niekerk has been working in the UK with Rotary there.

She is busy arranging a grant for AL which is hoped to be for 2012 in the region of 15000 pounds. She does not see us failing and she has continued her work for AL.