August 6, 2012

Submission to the Parliamentary Inquiry

Palliative care and home and community care services inquiry

Fiona Daroch-Speedie

Pictured: Val & Tony Speedie 4 days before Val passed away from secondary breast cancer. Tony was in chemotherapy for pancreatic cancer. Oct 2010

“The primary objective of hospice/palliative care is to enable people facing death:

- **to be as free as possible from unnecessary suffering (physical, emotional or spiritual);**
- **to maintain their dignity and independence throughout the experience;**
- **to be cared for in the environment of their choice;” quote from Palliative Care QLD website**

To the Parliamentary Inquiry Committee,

As a daughter who has lost both parents to cancer within the last 2 years, I have experienced first-hand the palliative care support, options and gaps within the system. One parent passed away in hospital while the other chose to pass away in the home, however due to significant shortfalls within the system this wasn't possible and he experienced incredible pain and distress before he passed away alone in an emergency ward. This is in direct violation of the primary objectives of palliative care.

As a result of this experience I am passionate about using my experience to assist and inform others to prevent a similar thing happening to them

I acknowledge that the majority of people within the system are incredible at their job and care so much about the families and patients however the system places too much ownership of knowledge into their hands when it should be a joint ownership.

It is my hope that by sharing my personal experiences and recommendations I can contribute towards highlighting the need for continued change within the palliative care arena.

Yours Sincerely,

Fiona Darroch-Speedie

Fiona Darroch-Speedie

[redacted]

Family Demographics:

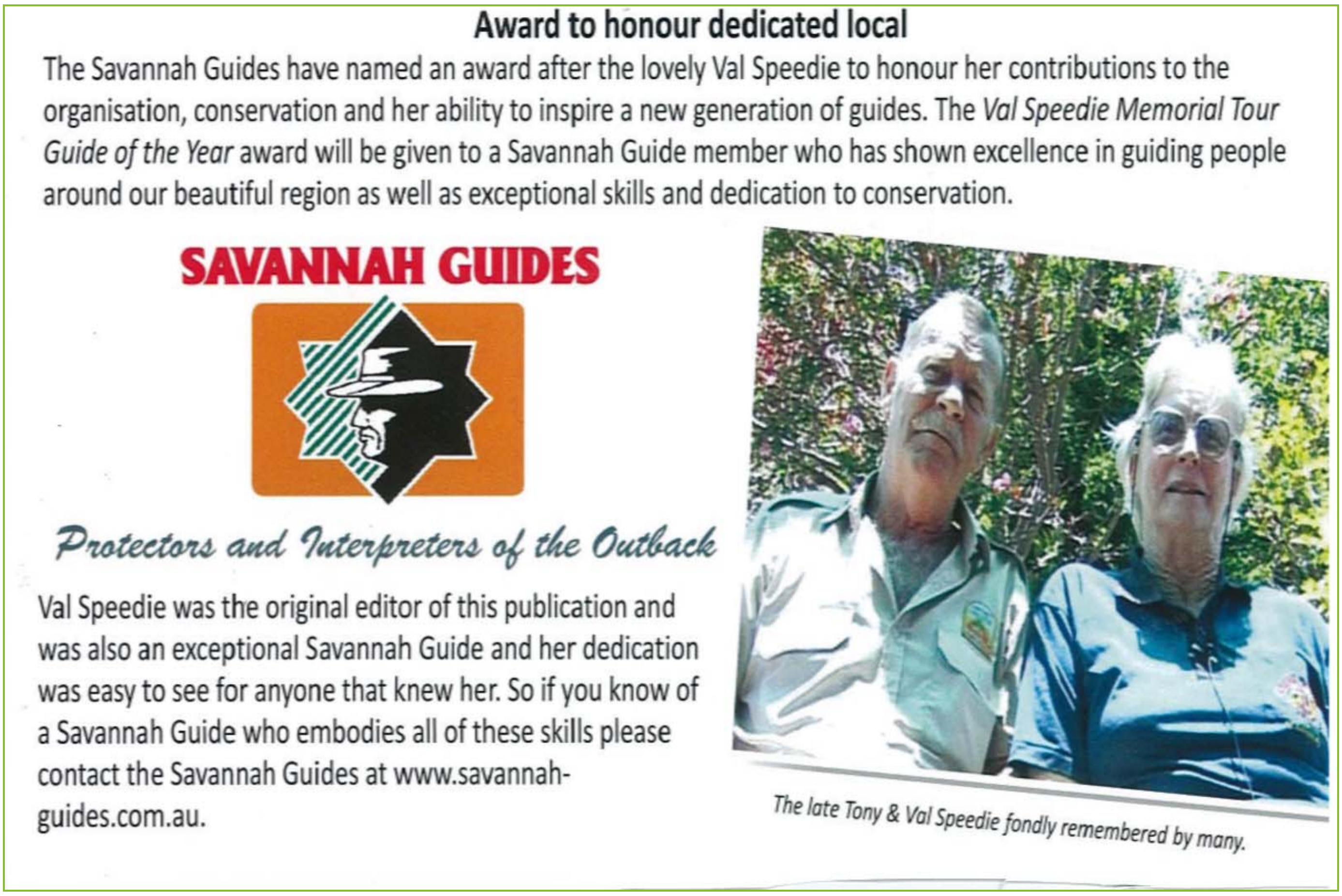
Margaret Valentine Speedie aged 68– Better known as Val Speedie or Mum
Savannah Guide and editor of the Northern Gulf Resource Management Group newsletter
(18/10/2010 RIP)

Thomas Anthony Speedie aged 71 – Better known as Tony or Dad
SavannahGuide (24/01/2012 RIP)

Fiona Margaret Darroch-Speedie – Daughter aged 42 divorced
Learning and Development Manager

[redacted]

[redacted]



Award to honour dedicated local

The Savannah Guides have named an award after the lovely Val Speedie to honour her contributions to the organisation, conservation and her ability to inspire a new generation of guides. The *Val Speedie Memorial Tour Guide of the Year* award will be given to a Savannah Guide member who has shown excellence in guiding people around our beautiful region as well as exceptional skills and dedication to conservation.

SAVANNAH GUIDES

Protectors and Interpreters of the Outback

Val Speedie was the original editor of this publication and was also an exceptional Savannah Guide and her dedication was easy to see for anyone that knew her. So if you know of a Savannah Guide who embodies all of these skills please contact the Savannah Guides at www.savannah-guides.com.au.

The late Tony & Val Speedie fondly remembered by many.

Our Story:

Mum first got breast cancer back in about 2004. A small lump that with radium treatment and hormones, went away. Mum stayed on the hormones for the recommended 5 years and had no idea of the high risks of it coming back after being clear for that long. She started getting sick again late 2009. She had trouble breathing which made walking and working on their 30 acre property difficult. She had always been fit as she was a renowned 'Savannah Guide' from the Gulf up in FNQ. At first Dr's couldn't find anything but she knew her body and persisted and when they finally did an oxygen test in Feb 2010 they found her lungs full of fluid. They withdrew nearly 3 litres the first time and when they tested the fluid found it contained evidence of secondary breast cancer.

The timing of this was especially poignant and sad as her family (myself, cousins, brother and sister in law, &her Mum) all put in together for a surprise Xmas present to get her &Dad a trip of a lifetime back to Scotland. Dad hadn't been back to Scotland since he was 21 and Mum had never been overseas at all and Dad had always wanted to show her his old home. We had thrown in a trip to Paris as well. The date of this trip was for June 2010 so Mum could spend her Birthday in Paris. Mum cried and couldn't believe her eyes when she realised that it wasn't a joke but a real gift. Unfortunately with Chemo and the spread of the disease, Mums low immune system meant that the trip had to be cancelled. I cried at that point and railed against how cruel fate was.

In June knowing Mum would be a bit low I travelled with my Aunt to FNQ to spend a weekend with Mum & dad for her Birthday. I bought hats, wigs, make-up scarfs etc. to have a girly photo shoot to lift Mums spirits. It worked and one of my favourite shots of her is with a rakish hat on top of a wig smiling and standing next to her favourite orchid which was blooming. (See below)

Treatment in FNQ was especially hard to organise for Mum & dad as it was a 3 hour driving trip up and down the infamous Gilles range to the Cairns base hospital. Where Mum had to spend hours waiting to get in, then get her chemo and then drive home again. We take for granted the resources and easy locality of them here in the SE.

As Mum despite her contagious optimism and spirits started to decline in July, Mum & Dad decided to sell and move in with me so they could be closer to family and also I had offered Dad a place to live with me because as I said, family has to stick together. My brother who was also here in Brisbane had a partner to help him with his grief but Dad and I would only had each other. Luckily a buyer came along quickly and the place sold and Mum, Dad and Mum's Mum (92) all packed up and drove the trip from FNQ to Brisbane. It was in the last couple of weeks of packing in August, that Dad began to feel unwell and was told to rush straight to the PA hospital as soon as he arrived in Brisbane. So Aug 31 they all arrived at my place, and the next day Dad was rushed into the hospital where we received his diagnosis of pancreatic cancer and he needed a Whipple operation ASAP.

So while poor Mum now spent half her days at Dads bedside and learning to navigate the roads toad n from the hospital, and the other half unpacking and looking after herself and her Mum, I was plunged into the confusing, world of palliative care for both parents.

Dad's operation was a resounding success and he was being hailed as the miracle man by Dr's and staff for the speed of his recovery. He of course attributed it to healthy country eating and living. He was home in less than 2 weeks. Sadly Mum & Dad got to spend about 2 days together in their new home trying to restart their life down here when Mum was rushed into hospital early October where she never returned. She passed away Oct 18th at 6.00pm.

(Mum supporting Dad at the PA hospital while he was waiting for his Whipple operation. He clearly is very yellow with Jaundice)

We never got the opportunity to use any of the palliative care service for Mum as she was only with me for a period of a month and a half. However the PA hospital did even in that short period of time, introduce me to social workers, home assessment physiotherapists etc.

She passed away in hospital with both Dad and myself holding her hand, talking to her and playing music. It was very peaceful and beautiful.

Dad on the other hand found hospital loud, noisy, disruptive, claustrophobic and stressful. He wanted to pass away at home. I was supportive of this wish as were the doctors and nurses. I was given brochures to read (that I later realised didn't contain any information that would have assisted me) and contact numbers. Every other community service including Blue Care, HACC, etc. all say to you "oh palliative care will be able to help you financially or resource-wise with that". However this is not the case, as I was told by one of the palliative care ladies from Logan South. They are short of funds and resources. Despite the fact that home care rather than hospital care is encouraged and cheaper for the state, as Dad detoriated and needed daily supervision and care, there just weren't enough resources to provide this. My work (2 hours away in the CBD) was very flexible with me working from home when I could, however I have a face to face role which made it difficult to juggle work commitments and home commitments. Blue Care was only able to come out every 3 days to help him drain his lung, and twice a week to supervise showers. That still left a gap of 2 days a week he was unsupervised. When I asked “what my options were, in order to provide him with this care?” I was told “that’s what families are for!”. As I am single and only have a brother who lives 2 hours away and also works full time, that wasn’t an option for me. I often wondered how Mum would have coped by herself if they had still been in FNQ on their property where resourcing is scarcer still.

Support in the home:

We were provided with some handrails installed into my home FOC. However walkers, shower seats, seat cushion, wheelchair and Blue Care visits were, although subsidised, still a cost to rent every month. His oxygen which he was always on when in hospital, was apparently not bad enough to require it in the home, so we had to pay for that also every month. Altogether it cost approx. $250 a month for his equipment and help.

Every day when I had to go to work and leave Dad alone I would be in a constant state of worry, what if he falls, what if he forgets to take his medication, what if he doesn’t eat, what if he can’t get out of his chair, etc..Every weekend and night was occupied with keeping him fed, comfortable and trying to amuse and interest his mind. Going for drives, walking slowly around markets, watching DVD’s. I had to stop Dance teaching (which was a second job at night and weekends I did to supplement my income and also to meet people and keep both mentally and physically fit). I used to teach between 2-6 classes a week. I had to stop that and therefore lost income and had no contact with people, friends, etc. other than at work.

Carer’s allowance:

This is one of the services that are supposed to be available to you to help financially. My experience with this wasn’t smooth or ideal. I first applied for this in September 2010 for both Mum & dad. I was told that it was unlikely I would get it as I worked fulltime and despite often working one day a week at home, I was away too much to be eligible. Surprising considering that I spent at least 8 hours a day caring for both. Then AFTER mum passed away (Centrelink was notified) I was told that I was accepted for Mum but declined for Dad. I have to admit after that I didn’t bother reapplying for Dad until September 2011 after Dad was re-admitted and his cancer had come back with a vengeance. I was finally accepted. After Dad passed away I notified them and they send me a letter confirming that Dad’s carer allowance was terminated however reminded me that Mum’s allowance I was apparently still getting.(this wasn’t true) I found this very upsetting and insensitive.

Events surrounding Mum’s end of life:

Mum was admitted for the last time to the Princess Alexandra hospital on Sunday the 10th of October. Her legs were swollen and constantly leaking, she was alternatively ravenous for cravings (eg) watermelon and nauseous. Her mind started to wander on Friday and she started to fret that her list of things to do wouldn’t get done. By Saturday she was beginning to vomit and slip in and out of a coma. Sunday both my Dad and brother visited her but she didn’t know them. Monday the 18th of October at 6.00pm with dad and myself holding her hand, pain managed; listening to her favourite songs on an ipod she took her last breath. Her passing away was peaceful and had none of the distressing elements that characterised my Dad’s final days.

Events surrounding Dad’s end of life:

Dad after spending so much time in hospital for his operation and chemotherapy and being a country boy, felt claustrophobic in hospital as well as distressed due to the oncology wards mostly being filled with the palliative care patients who normally exhibit some pretty nasty, noisy and scary symptoms. He made the choice (which I supported) to pass away at my home, with his dog, Mum's perfume scenting the air and watching the mountains and feeling the fresh air. However this idyllic scene was NOT how it panned out!

We had a Dr come out to see Dad on the Thursday the 19th of January as he was becoming very sluggish and kept drifting off. He had two of his closest friends from FNQ visiting him which allowed me to go to work, The Dr (I wasn't there) apparently said to say our goodbyes and make the final plans as he probably only had 48 hours left. Earlier that week he had been walking around shopping!

So Friday night he had a big teleconference with his cousins and brother in WA, my brother came over and his friends from FNQ all played his favourite DVD, songs, laughed joked, cried and said to say hello to Mum when he saw her shortly.

He went into a coma Friday night and never regained consciousness. But it was far from peaceful!

Saturday he was still with us so after his friends left for the airport I was on my own with Dad. That's when the problems started to become apparent. ..

How do you manage to get someone to take their oral medication for pain management when they are unconscious?You don't, you have to have a'driver pack' approved by a Dr, organised to give intravenous pain injections.

How do you know this?It's not in any brochure or info pack. So the only way to know (before you need it) is if your Dr tells you.

How do you get this organised and quickly? With great difficulty on a weekend!!!

The result? Dad spent approx. 36 hours without pain medication. Now he had pancreatic cancer which is incredibly painful. It was so painful for him that despite being unconscious he was constantly calling out my name, holding out his hand begging to get his pills. I had to sit by him constantly during that time, lying to him by saying that it was coming really soon crying while I said it! I had no sleep during that time and ended up calling my brother at 3.00am Sunday morning for help as Dad had fallen tot eh floor, after somehow getting out of bed, we realised later that it was because he had wet the bed. Another thing we were unprepared for) and I needed assistance to lift him, keep him calm, change sheets, try and find something to protect both the bed and Dad from more accidents.

A driver pack wasn't installed until 11.30am Sunday morning and he wasn't able to swallow any pills after Friday night.

The Blue care nurse who helped install the driver pack (they have to wait for Doctor authorisation) was wonderful. She gave us extra break out pain injections for Dad in case his pain requirement increased. I got 2 hours rest after that as Dad finally seemed to be comfortable. Wishful thinking that the drama was over.

He began to get restless again, so following instructions I gave him an extra injection. My brother had to hold him still to facilitate this as you can't inject a long sharp needle into a small sensitive catheter if the patient moves at all. That settled him for another hour, then he again began groaning and calling out. Another injection followed by a phone call because the way this was going if Dad held on until Monday morning we wouldn't have enough pain medication. The Blue Care nurse, although now technically off duty, came back and gave us some more pre-prepared needles.

Dad's requirements increased almost half hourly and he lost control of his bladder again. I was especially distressed by this as Dad had been very private and had been adamant that his daughter would never shower, dress or toilet him as it was improper and undignified. I knew he would have been really upset by my having to manage the incontinence. The Blue Care nurse also when she returned, brought some incontinent pants with her to help us. (if we had been told to be prepared for this we could have had some on hand)

By the time Monday morning came around, I had been up for nearly 72 hours without sleep. Dad wasn't comfortable, he was constantly groaning, trying to get up and clearly not peaceful or happy, and we had run out of break through pain injections. My brother and I felt that we weren't able to provide adequate or appropriate care so at 2.00am we called the palliative care number to ask for an ambulance to transfer him to hospital. I was given arguments, objections and made to feel like I was giving up on Dad. She talked me through being able to make up more injections from ampules the Blue Care nurse had left. We left it another couple of hours but exhausted and upset at what we were witnessing with Dad's deterioration we called again. I had to be very insistent and firm to get the ambulance.

They arrived shortly and ascertained he was unresponsive and transferred him to Beaudesert hospital.

I had some sleep until about 9.00am then drove into the hospital where Dad was being kept in the emergency area as there was no room in the wards. The nurses were amazing and carried up a big armchair from their tea room for me to relax in while holding Dad's hand. He was resting much more comfortably and wasn't groaning at all, however I felt so bad that I wasn't following his wishes to be at home. I stayed with him until about 4.00pm talking to him and playing some music. Luckily no one else came into the emergency ward so it was quite quiet.

I got the phone call at 12.03am Tuesday morning the 24th of January to say he had taken his last breath. I cried not only in relief that his suffering was over finally and that he was now with his beloved wife, but I cried with guilt that he has passed away alone in a strange hospital completely against his expressed wishes.

In hindsight I am really angry that the majority of issues and problems experiences could have been avoided by some practical advice and forethought by the attending Dr who came out on the Thursday before. If they had:

a) Organised for a driver pack to manage the pain, with the knowledge that once someone becomes unconscious you can no longer feed them pills as there is a danger of choking.
b) Let us know that Dad may lose control of his bladder (not after death, we did know that) while unconscious, so again we could have been on the lookout for it and therefore planned for it to be fairly simple procedure instead of having to try and move a full grown unresponsive man out of bed, change sheets, wipe him down, and re-position him.
c) Indicated that if Dad was still with us by the weekend, that palliative care, pharmaceutical and medical services are reduced and restricted.
d) Let me know that his pain needs may escalate and again have a plan in place for that.
e) I also felt that when I did ring up to say 'Help!' I can't cope anymore as I'm sleep deprived and in distress and shock at seeing Dad so uncomfortable and in pain…that I was made to feel weak and silly and that I was giving up on him.

In conclusion:

If"the primary objective of hospice/palliative care is to enable people facing death:

- ***to be as free as possible from unnecessary suffering (physical, emotional or spiritual);***
- ***to maintain their dignity and independence throughout the experience;***
- ***to be cared for in the environment of their choice;"***quote from Palliative Care QLD website

Then this failed on all accounts in my Dad’s case. The following recommendations based on the terms of reference I believe will help prevent this happening to others.

Terms of Reference:

1. *That the Health and Community Services Committee inquire into and report on Queensland's chronic, frail and palliative care services.*
2. *That, in undertaking this inquiry, the committee should consider:*

    - *the capacity and future needs of these services (including children and adolescents palliative care)*
    - *the effectiveness, efficiency and adequacy of palliative, frail and chronic care services*
    - *examine opportunities for reforms to improve collaboration and cooperation between chronic, disability and other health services, and*
    - *consideration of segmenting the current Home and Community Service system based on age of the client, needs of the client, their carer and the providers.*

3. *Further, that the committee take public submissions and consult with key industry groups, carers, health workers and relevant experts.*
4. *The committee is to report to the Legislative Assembly by 28 February 2013.*

Palliative care is defined by the World Health Organization as:

> *…. an approach that improves the quality of life of patients and their families facing the problems associated with life - threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*

Palliative care:

- *provides relief from pain and other distressing symptoms*

- *affirms life and regards dying as a normal process*

- *intends neither to hasten or postpone death*

- *integrates the psychological and spiritual aspects of patient care*

- *offers a support system to help patients live as actively as possible until death*

- *offers a support system to help the family cope during the patients illness and in their own bereavement*

National palliative care strategy

State, Territory and Commonwealth Health Ministers endorsed the National Palliative Care Strategy – Supporting Australians to Live Well at the End of Life in November 2010. The Strategy recognises that the demand for high quality palliative care services will inevitably increase, and that palliative care services are provided in almost all parts of the health and human services sector. To meet increasing demand, the Strategy focuses on four goal areas:

- *awareness and understanding of dying, death, grief, bereavement and loss, to support better access to appropriate, timely services*

- *appropriateness and effectiveness, ensuring the right approach, at the right time in the most suitable setting; providing services that are supported by evidence and meet the needs of patients and their families*

- *leadership and governance, to ensure implementation and improvement of services; in a diverse service system strong accountable leadership and governance is particularly important*

- *capacity and capability to provide effective care services by having sufficient skilled people in the right place with systems to support high quality care, and sufficient resources, facilities and equipment to deliver care.*

Response to the following Terms of Reference:

2. *That, in undertaking this inquiry, the committee should consider:*

   • the effectiveness, efficiency and adequacy of palliative, frail and chronic care services

➢ *provides relief from pain and other distressing symptoms (from WHOdefinition)*

➢ *appropriateness and effectiveness, ensuring the right approach, at the right time in the most suitable setting; providing services that are supported by evidence and meet the needs of patients and their families (from National Palliative Care Strategy)*

- Currently there is no information in existing palliative care brochures about the need to have a plan to transition from oral medication to intravenous. This has a huge impact on their levels of comfort and is a basic need that should be met.
- Lack of consistency with recommendations from different service providers (e.g.) Blue Care, HACC and Palliative care.
- Lack of understanding within the sector, about funding, services available and options, means carers are often and unintentionally misled and misdirected.
- There is no list of FAQ’s for carers or families to ask their Dr’s or palliative care professionals. This removes the power or knowledge from families and gives it all to the palliative care team which is inequitable and unsustainable.
- Obvious lack of common systems and information between sector and government agencies (eg) Centrelink letter sent still listing Mum as being cared for by me, and me still getting an allowance for her 15 months after her death. Also I have just received a survey for Dad to fill out from Logan Palliative care, even though I had offers of counselling from social workers for grief after Dad died.

Recommendations:

Include in end of life information packs, brochures and other sources; 5 key points for families to be aware of, so they can ask for it, plan for it and where necessary insist on it. But most importantly not be ignorant about it and therefore not be 100% reliant on the medical staff who although well intentioned, are usually overworked and under resourced.

1. If your loved one is currently on oral pain medication, as they approach end of life they will become unable to voluntarily swallow, so speak to

yourPalliative care professional about transitioning to an intravenous approach early to avoid any issues.

2. Towards the endthey may lose control of their bladders, so if you are prepared for this, you and they can be more comfortable and remain dignified.
3. You should arrange to have help and assistance with you around this time, not just for emotional support but to help with lifting and moving your loved one as well as alternating rest periods.
4. If the end looks like it is approaching over a weekend, ask what assistance and reduced services (if any) there may be and the implications of those.
5. Be aware that (especially if cancer is involved) that their pain needs may increase substantially so make sure you have access to break out pain medication

Continuity and dissemination of critical information:

- The sector demonstrates a lack of integration of services delivery. There is generally a lack of communication between both government and non-government service providers which translates to inconsistent information distribution and ignorance. In practical terms carers often miss out on important information that may be crucial to assisting them and their needs.
- Critical information about the availability of services and referral to such services are often overlooked.
- Lack of consistent dissemination of information regarding entitlements and services for carers.

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