

First Prize Winner of the Inaugural Kogarah Lions Club Healing Narrative Award 2011

The gift of listening to Rose

By Beate Steller

A reflective essay which highlights the therapeutic benefits of listening to a patient's individual story or narrative

It takes many ears to listen and various shapes of mirrors need to be held up to reflect a person's story. The need to tell one's narrative becomes especially critical when facing a life threatening condition. There is an urgency to ensure that one's story is heard and all our natural defences and social conditioning that might have normally inhibited our telling, get's swept aside. Everyone who was part of Rose's care plan, the doctors, nurses, volunteers, cleaners and pastoral carers and anyone else who crossed her path at St George Hospital helped her to tell her story, make meaning and negotiate an unknown landscape that she would only need to cross just the once. The following will capture what it takes to listen to the stories that many patients need to tell, to attain rich and accurate interpretations of the stories and to grasp the plights of patient's in all their complexity.

Rose was a 74 year old woman from German decent, a proud mother of six who presented to St George Hospital with all the symptoms that proclaimed to her that she had pancreatic carcinoma. 15 years ago she was diagnosed with cancer of the stomach and had made a remarkable recovery. Now this. Would her recovery be equally as successful, her care of the same standard and did she have the strength to face all those uncertainties again? These are some of the questions she raised when I visited her wearing my Pastoral Carer's hat. I travelled with Rose over a period of nine month through her ups and downs and tried my best to listen to her story and support her in the best way I could.

Very quickly after the diagnosis Rose had surgery hoping they could remove the cancer, but when she was wheeled back into the ward after her operation she was told that it was an open and shut case. She was in and out of hospital having a number of stents inserted to alleviate her symptoms and give her more time. Rose spend many hours discussing with oncologists about her next step on this journey. After much soul searching she agreed to go on a vaccination trail that could possibly arrest the growth of her cancer. In the middle of the treatment she returned back to Germany to say good bye to her son and family and also celebrated her 50th golden wedding anniversary. Four months passed and Rose was referred to the Palliative Care Team at Calvary hospital. Two month later she died peacefully with her family at home.

When listening to Rose many issues were raised over the months. Her main concern was to ensure her husband Heinz would have everything in place when she would not be there to take care of him anymore. She was the traditional homemaker, cook, cleaner and social organiser and had learned this role well over the many years. Although Heinz was a competent scientist and was travelling regularly throughout the world, she wanted to make sure he had a little home that would be close to his children. The current home was a big five bedroom house that had served its purpose in the past to accommodate a big family. It would not be suitable for Heinz in the future. So many hours were spent listening to Rose and helping her clarify what she wanted to do. She

was single minded and part of the listening was helping her to make lists of things that were important for her at this stage of her life. It seemed like a very clear sense of putting your “house” into order. Little practical things like emptying out boxes in the attic that she had not had a chance ‘to get to’ for the last 30 years were included on the list. She asked her family to get behind her and this they did. She was amazed at their co-operation, as in the past she had not received such a positive response when she had asked for help. She said this gave her a great sense of peace. Interestingly, she ended up completing most things on her ‘to do’ list, but the boxes from the move 30 years ago from Germany to Australia were still up in the attic when she died. No one seemed to mind.

Another issue Rose struggled with was to constantly having to make decisions about her treatment and care. The choices she had to make seemed to be endless and at times, she said, she wished someone would simply decide her treatment plan for her. She was an intelligent lady, had a university degree behind her and certainly was a critical thinker. However, she was sometimes indecisive, always weighing up the pros and cons of any decision. I sometimes came with her when she visited her oncologist. He would gently pull out his chair so he could sit next to her, instead of talking to her behind his desk. She would hold up her lists of questions and bits of paper of what Heinz had printed off the internet. The doctor’s listening skills were excellent and helped Rose to work out the direction of her story. He never pushed her but instead acknowledged that she might need more time to think things over. The visits with the Doctor were never short and the patience and kindness of the man was very appreciated by her family.

Making choices is never easy. Not did Rose only have plenty of information to choose from, but more importantly, the expectations of “her family” were the things that made the decision process complex. Listening to her, and making a point to reflect her story without giving advice or allowing my own values or experience influence my listening was of greatest value to her. Her husband and family wanted her to try any treatment if possible to extend her life. This is a natural response of someone who loves another and does not want to let them go. So Rose went along with their wish as said she did not want to disappoint her loved ones. At the same time she said that she had lived a full life and she was ‘tired and worn out’. She was not afraid to die. However she seemed to have trouble in making her own decisions. This raised another issue for her which begged the question ‘Is this my treatment or my families?’.

This issue of questioning the ownership of the patient’s treatment plan is part of the complexities of honouring the patient’s narrative. This was not just about Rose’s story, it was also about Heinz and their 6 children and 16 grandchildren and the many other people who made up Rose’s story. Each person was part of Rose’s web of life and so when we listen to a patient’s narrative we get insight to all the different chapter’s and interpretations, versions and even new editions of how Rose’s life is told and interpreted. All I could do is listen, validate her experience and acknowledge the complexities involved, remind her that there are no easy answers to difficult questions and that the “road is only travelled by walking”.

Heinz was still hoping that the vaccination program – the use of Telomerase- would heal Rose and so she would “live until the age of 100 ”. Denial is a healthy and important protective mechanism when we live with anticipatory grief. It protects us from immense pain and keeps us going when life seems at times unbearable. One day Rose spoke with me became very upset and frustrated, as she felt she could not talk with Heinz how she is ‘really going’. “He is constantly telling me to take those supplements and things that make me live forever and he will not listen to me when I am trying to tell me that I am running out of strength”. I sensed that she was feeling upset and alone

on this journey and no one wanted to walk with her as it was too difficult. I acknowledged her feelings and she began to cry. I reminded her that we needed different people who have different roles at specific times in our lives as our loved ones cannot be everything to us all of the time. I explained that usually midwives are much more welcomed and helpful to birthing mothers than the fathers of the babies being born. This does not mean fathers don't care; they are just too close to the experience and in fact need support themselves when they see their partner in pain and feeling out of control. It is the same with the dying process. We need people around us who are familiar with this last stage of life and who can listen without being too closely connected to the story.

Suffering is complex and with our understanding of wholistic pain, we aim to attend to the physical, emotional, social and spiritual needs of a person when trying to alleviate suffering. Fortunately Rose's suffering was primarily physical pain which she talked about with the doctors. She was prescribed four hourly panadol initially. Rose complained to me about this as she could not get her head around the idea of taking medication when you were not actually feeling pain. All her life she had learned that you would be given medication to alleviate pain after you had experienced it. So being pro-active and taking analgesic in advance was a concept that took her months to embrace. Once she accepted this her pain was well managed. Rose talked about her fear that she might suffer uncontrollable pain closer to her dying, but her palliative care team managed this well for her. A greater sense of calm came over her once she talked to the doctors and nurses about it and was informed about how this would be managed if it would arise. The fear in her voice diminished once she was able to name the fear which she had kept to herself. The listening externalised this fear for her and brought a great sense of calm.

Since my journey with Rose's illness stretched over many months my feelings during and at the end of our many talks were very mixed. To be allowed to travel along someone's paths during their illness is a privilege and certainly always a learning experience. So for me it was dealing with my insights and interpretations of her story, feeling touched when listening to Rose's experience and my own sadness that was triggered.

At times when so much 'fixing' and 'helping' was offered to Rose I wondered what difference my listening made in Rose's life. It gave her confidence and courage as I was comfortable to simply 'be there' with her. This I was only able to do because of the many years I have travelled along people's journey during their last stage of their life and having learned that the simple act of listening can actually make a difference. I had learned that holding her silence quietly, faithfully turning up and spending time together, clarifying her thoughts and reflecting difficult feelings are therapeutic benefits of listening.

Holding up a mirror, as mentioned at the beginning of this story, means allowing a person to express their hidden thoughts and truth about their life and helping them to see their story for themselves. Often when we are in a crisis we lose sight of who we are and what we need and want to do. By gently and tentatively asking questions that allows us to reconnect with what is important to us is a helpful and meaning full part of listening.

When I asked Rose if she had any concerns or fears about her dying she said that she was not afraid as she had a strong faith in God. However, as time went on, she once said that she was too tired to pray now and there was a sense that she had no certainty as such about what would happen to her after she took her last breath. She said that her dying was the final and greatest test of her faith. She talked about remembering her childhood prayers more vividly in her last days and that the simple childlike words of these prayers were in fact more meaningful to her now than ever.

The most difficult challenge during my discussions with Rose was when she talked about the loneliness of her journey. In the end we have to face our last breath on our own. It made me aware of my limitation as although I was willing to listen to Rose and support her I could not fully walk in her shoes. I could only walk beside her.

What affected me the most when listening to Rose's story was that I was not just her Pastoral Carer, but I was also her daughter. I had to manage my own emotions and values as Rose explored hers. I had to step aside at times and refocus. The narrative of her journey was intrinsically part of my own journey. This of course happens every time I travel with someone on their journey. As Rose was my patient and also my mother this became even more profound. I could not have listened to Rose the way I was able to if it was not for the support other people gave me as they listened to my narrative. Many people kindly lend me their ears and also held up a mirror to me so I did not get lost and remembered who I was. There were times were I failed to listen to her as I got too enmeshed in the drama of her story and reacted to Rose due to my own pain. Listening to another when our emotions are high is certainly challenging and an area I have a lot of growing to do.

With gratitude I was able to listen to Rose's story which allowed her to make sense of her illness and final stage of her life. It helped her to make more autonomous decisions and to clarify her priorities. It also enriched my life as I learned a lot about a person that I had known for many years as my mother. Aiming for objective and non-judgemental listening wearing my Pastoral Carer's hat allowed me to see Rose in a new light and appreciate her narrative for who she was.

Accompanying Rose along her final journey raised many questions for her. Listening does not provide the listener with answers. Instead listening can instil some hope and trust to love the questions that come up on life's final stage. As the German poet Rainer Maria Rilke 1920 so beautifully expresses:

“Be patient toward all that is unsolved in your heart.
Try to love the questions themselves.
Do not seek the answers, which cannot be given
because you would not be able to live them.
And the point is to live everything. Live the questions now.
Perhaps then you will gradually without knowing it,
live along some distant day into the answers.”

20th January 2011, 4th Anniversary of Rose's Homecoming