

The Quest

Sue Walthert

Sue Walthert is a Dunedin GP and delivered this oration at the 2008 RNZCGP Conference in Queenstown.



Thank you for asking me to be here tonight. I wish to acknowledge people who helped me find the stories; my brother Andrew Divett, Lucy O'Hagan and Pat Farry, and those who gave permission for me to tell their story – especially my daughter Emma and my friend Odette.

Once upon a time in a beautiful land, the woodcutter's daughter lay gravely ill. Each day, little by little, she was losing the light. The woodcutter and his wife sat by her side and prayed. On the 8th day the girl could see no more. The wise men came and said: *'We have only two cures left and we don't know which one is the right one.'*

It was our daughter Emma, aged 16, who lay gravely ill with meningitis. She lost her vision after eight days in hospital. The last two drugs were dexamethasone and anti tuberculosis drugs. Her diagnosis: TB or autoimmune meningitis. Emma gradually recovered her sight, but it took three long years for her to gain back her full function.

Her graduating Bachelor of Arts was one of the thrills of our lives. She is now 25, enjoying her 'OE' in Switzerland.

It was Sod's Law that the first patient I saw when I went back to practice, was a teenager who used Emma's exact same words to describe her symptoms. I asked myself: could I, should I, continue to see her, or pass her on to another doctor. I did see

her. This girl's visual acuity and discs were normal, she just needed reassurance.

Many of you will remember your Orator Pat Farry, here in Queenstown 20 years ago. He encouraged GPs to be humble, compassionate, respectful, able to share power, and proud of ourselves because, he said: *'No one else can do it like you can.'* Pat meant, no one can practise medicine the way GPs can, but forgive me if I use it another way. If the woodcutter's wife had continued with her consultation that day, no one else would have been able to do it like she could. We have all been in this situation: a unique happening, where a recent, very personal experience in our own life is mirrored by our patient's story.

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We know there are dangers in the entanglement of our personal life in our practice of medicine. Textbooks emphasise self-knowledge so as to limit the negative impact of ourselves on the doctor-patient relationship, but rarely do they comment on the positive impacts. Our much missed colleague Jan Breward, who died 10 years ago, alluded to the positive, when he said: *'While total awareness of self is not attainable, striving to know the self of the doctor, using this knowledge to enhance the interactions with others and improve our own quality of life is why we have peer groups.'*

We know that self-awareness and self-knowledge are vital to being able

to use ourselves in a way that is safe for the patient and safe for us. We also know about the concept of being wounded by our life experiences. In my case, it was seeing my daughter near death and realising her doctors had almost exhausted the treatment possibilities. But what do we call what lies beyond that wounding, that which enables us to use those spectacular spills safely? And, if something lies beyond that wounding, how do we get there?

This is sounding like a Quest.

The philosopher Immanuel Kant said *'science is organised knowledge, and wisdom is organised life.'* Arthur Frank, author of *'The Wounded Storyteller'*¹ talks about organising life by learning how to organise the stories people tell. *Restitution* stories are about getting sick and then getting better. Emma's story is one of these. *Chaos* stories imagine life never getting better. *Quest* stories find meaning in illness. Illness becomes a journey and telling the narrative allows patients to find their own voice.

Frank says that we should listen in a way that will allow us to hear someone's story – not just about their body, but through their body. Empathic listening. The very process of telling the story creates another story, and without us saying a word, something changes. We are all unique, with our own unique life stories. If we empathically hear our own stories, like we hear our patients', does something change for ourselves? Could this be a part of the Quest?

I've found over the years, thinking about, writing about, and telling the stories of my thrills and spills has

moved me forwards, even if I don't quite know where I am heading. The thrills and spills of my life have been rich pickings for the learning feast I have enjoyed over the years. Thankfully, the thrills have been many. The woodcutter, my wonderful husband Edi, and our two Swiss-Kiwi kids top the list. Our second child, Jeremy is here tonight, 23 and living just down the road, committed to encouraging teamwork in rural health in his work as an occupational therapist.

My spills have been many and spectacular. I have spent far too long being the patient! Indeed family therapist, Janet Christie Seeley's light-hearted comment could apply to me: *'Don't get well too soon – your suffering is an inspiration to us all.'* But I don't want my suffering to be the inspiration, rather the rich pickings, as I, unlike Humpty Dumpty, attempt to put myself back together again.

Time for another story:

Once upon a time, there was a beautiful dancer. When she danced it was as if she had harnessed the sun. But she was not always like this. At her birth, a mean wizard stole her and kept her imprisoned. She escaped with her family to the forest, grew up and had children of her own. But the darkness stole her and locked her, once again,

in the wizard's castle. *'I just want to be left to dance,'* she told a passing robin. The little bird wanted to help, but didn't know how to set her free. One day a wise man passed by and heard her plaintive call for help. He called up to her: *'you know what to do. Trust in your body and all will be well.'* The dancer felt her spirits soar and she looked hard to find what was within her. *'It's in the dance,'* said the wise man. So she started to dance. As she danced the light became so powerful, it melted

away the bars of her window. The dancer, her children and the little bird flew over the forest to a land far away where they lived happily.

For most of us, this story would be enough for one lifetime. But in this story the dancer's life started over and over again.

She would be locked in the dark room again, learn to dance and fly away again, only to be tossed back to the beginning time after time. But gradually, something began to change. While the dark room remained the same, the wizard grew kinder. He had witnessed her dancing and he was

touched by it. Finally one day, the dancer found she could dance no longer. The little bird tried to rouse her. *'Why can't you harness the sun and keep dancing?'* *'Because the dancing and the darkness have made me tired. I need to rest and soon I will*

fade away into the light. My children need the light now, I am happy to see them dance.' When she faded away into the light, her family, the little bird and even the wizard were sad until they realised they would

always be able to feel how they felt, when they watched her dance.

This is Odette's story.

Odette opened our Dunedin conference in 2003. She helped us understand what patients hope for in times of hopelessness. She has suffered metastatic melanoma for over eight years. Odette was my patient until she finished her MFA. After that we became friends. She was the last of undiagnosed triplets, born as an added extra, after the doctor told her mother in no uncertain terms, there was nothing left. Her birth was however a delightful surprise to her lov-

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ing parents. Odette's birth was a metaphor for her life. She was denied her existence and her entry into the world by men in white coats, doctors. Many years later, she was denied her hope of life by those same men in white coats when she was told that her metastatic melanoma was incurable. It took me a long time to learn that words landed differently on Odette. Once I understood the story of her birth, I understood why it was so difficult for Odette to feel heard.

Odette introduced me to Ian Gawler, the wise man in the fairytale. The charismatic Australian vet who looks like a guru, until you talk with him and realise he is just an Aussie bloke, with a really good yarn to tell about how he survived his own cancer. Odette used his techniques – eating well, thinking well and meditating – for many years, but would be tossed back to the beginning, locked in the dark room, with each melanoma recurrence. But she refused to stop her dancing. *'I want it to be about living right up to the end,'* she told me. Her doctors learned over time, like the wizard did, to soften their language, listen to her words and take their cue from her.

Odette died yesterday morning. Her death was as she had hoped for, a gentle closing of the eyes in the company of her loving family.

Odette's story is a true Quest story. One Quest was to understand herself within the context

of her own life. Another Quest was to use her experience to help others, especially the doctors: teach us to be careful about how we use words. Another Quest was to rise transformed above her suffering, like the phoenix rising out of the ashes.

One of the risks in a Quest story like Ian Gawler's is that it can make others feel they have failed, if they fail to rise out of their own ashes. Although Odette courageously survived longer than many with a simi-

lar story, she told me just a few days ago that she felt sometimes she had not tried hard enough. How can a doctor or a friend respond to that? Perhaps the only words to use, are those of Paul Ricoer: *'We can be the narrator of our own story but we are not the author of our life.'*

Odette's belief in Gawler's testimony had a profound influence on me, as a GP and a person. I visited the Gawler foundation on a retreat for health professionals six years ago. The doctor part of me wanted to find out if this was a place I could trust. I came home happy to endorse Odette's self-help programme. The sort of advice Gawler gives, is what I call 'fridge magnet psychology': *'Live as if there is no tomorrow,'* etc. Now, my own fridge has a magnet that reads *'When the going gets tough, the tough eat chocolate.'*

I came home asking Edi and myself, *'Why wait to get cancer to make changes in your life?'* So for four years I tried to be a vegetarian, meditated a lot more and Edi and I took a long look at our lives. I worked less and promised never to organise a conference again and Edi bought himself a piece of land and a little yellow digger! Just as we were settling into our good life, in April last

year, the little bird in Odette's story fell off her perch again!

I was diagnosed with Her 2 Positive breast cancer. I have had surgery and chemo-

therapy and am struggling through 12 months Herceptin treatment. But, I can't tell you this story. Maybe I could paint you a picture. It would be a Picasso, yes, a chaotic Picasso. Can you see my painting? The colours are very muddy. Like the pathway Moses cleared through the Red Sea, breast cancer treatment is a bit muddy! *'We are going to save your life, but we will cut off your breasts, feed you poison, force you into menopause and give you drugs that make*

you fat even though we tell you to stay slim. And then we will send you the bill for Herceptin. But it might save your life.'

The 17th century grand Duke of Florence's own doctor said *'Most serene highness, I take your money not for my services as a doctor but as a guard, to prevent some young man who believes everything he reads in books from coming along and stuffing something down the patients which kills them.'* Obviously describing oncologists!

Can you see the women in my painting? Women who have endured breast cancer through the ages: an Egyptian queen, Anne of Austria, two colleagues from my own peer group, my mother, her mother and her sister. They embrace me, and I see myself stiffen in their welcoming arms. The only embrace I want is my mother's. She is a recycled teenager turning 88 on Saturday, and I want to be like her.

Can you see Herceptin in my painting? After chemotherapy, when I finally felt strong enough to look at the research on Herceptin, I found myself hungry for the truth. This part of my story I can tell. So I googled my own cancer, wrote about it and had it published in the *Sunday Star Times*, the *NZ Doctor* and the *Pink Magazine*, encouraged by my oncologist, who said I could get away with saying things he couldn't. Evan Esar calls a statistician, *'a man who believes figures don't lie, but admits that under further analysis some of them won't stand up either.'* I found Pharmac's interpretation of the Herceptin figures didn't stand up. Neither did the way the media presented Her2+ breast cancer as a death sentence and Herceptin as a life saver. The colours of the patient voice stand proud in my painting, especially if they can move Pharmac out of their mud!

Can you see the frame around my painting? A crisis always looks better if you can reframe it. My son Jeremy suggested that the surgeon, as well as sorting out my ample tummy to re-

Proust tells us 'we don't receive wisdom; we must discover it for ourselves after a journey that no one can take for us or spare us'

make one breast, could remove the other breast and sort out my ample bottom at the same time. Even Her2+ can be reframed: 'Her positive too' or 'Positive to Her'. But I have not yet managed to reframe the moment I realised I had left my breast prosthesis at home! Sometimes all you can do is laugh. The frame I have put around my Picasso is old and worn. It's the one I used years ago when I turned my chronic pain story into an exciting voyage of self-discovery. I still suffer this pain but the frame allows me to cope. But, by reusing this frame, I have to be careful not to let the colours of chronic pain's incurability muddy the colours of my cancer.

Can you see the book in my painting? Confucius said, 'Two things stand like stone. Kindness in another's trouble, courage in your own.' Odette and I talked about writing our book: its title could be 'Standing Like Stone' for each other.

And, if a patient asked me, do I believe diet, thinking well and meditation could cure cancer, what would I say? What I do is always more revealing than what I say. You might watch me here at this conference to see what I do. Proust tells us 'we don't receive wisdom; we must discover it for ourselves after a journey that no one can take for us or spare us.' I have an open mind but not so open that I forgo evidenced-based medicine. Research shows me that surviving breast cancer has something to

do with being fit, having a low fat diet and a low weight, but much more than that, we don't yet know. As you can see, I still enjoy chocolate!

Can you see the doctor in the painting? There are many kindly doctors and nurses there. But my Doctor Self is still muddy. I am teaching medicine, not practising it just now. I need to wait a little while longer until the mud under my feet has dried some more. And when I see my first patient with Her2+ breast cancer, how will I feel? You know on your computer when you are about to disconnect the hardware. A wee pop-up appears and asks you to go through a process before disconnecting to protect your hardware. Well, I know a gigantic pop-up will appear and remind me there are things I can do, attitudes I can take, that will ensure it is safe for me and the patient. The Picasso will always be there, but I can be a better doctor if I've sorted out the chaos. The woodcutter's wife had gone through this process. Peer group had helped her bracket the emotions from her traumatic experience and with her newly refreshed neurological skills, she could do this consultation, like no one else could. But don't be persuaded that it will stay this way. We work with nature, things can and do change. I have to remind myself to be humble and check the pop-up, every time, just in case it has changed again.

And where is the Quest in my painting? Well, the Quest isn't in the painting. It's the other way round. The painting and the fairy tales are in my Quest. It's the Quest that comes after our wounding.

And where are we going? I used to think the destination was the most important bit. But now, I realise, it's the Quest I've grown to love.

Each of us has our own unique Quest. It's why no one else can do it like you or I can. But while our Quest is our own, we are not always on our own. During this conference, please, take some time to think of all the people who have accompanied you on your Quest, and thank them.

I want to leave you with some hope for our future. In the Dunedin School of Medicine's new second year curriculum, we teach reflective writing. Daniel, four months into his medical career, reflects after hearing a patient's chaos story: 'I don't feel as if I have the skills to respond constructively to such a conversation. What use is there in extracting a comprehensive illness experience if I can't respond to it? This is an area of concern that I will need to work on throughout my training if I am to be an effective doctor.'

A young healer begins his Quest to become the wise healer.

Sue Walthert
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References

1. Frank A. The wounded storyteller: Body, illness, and ethics. Chicago: University of Chicago Press; 1995.

Spirituality and biopsychosocial medicine

'Based on the consistent importance of religion and spirituality to health, Onarecker and Sterling proposed that the biopsychosocial model be revised to include spirituality. This model is consistent with the definition of holism that "deals with health problems in their physical, psychological, social, cultural, and existential dimensions." In addition to a direct association between spirituality and clinical parameters, associations between biopsychosocial symptoms and spiritual factors suggest that spiritual symptoms may act synergistically with these other symptom dimensions to affect health.'

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