

## **“Just ask Judi”**

### **A patient’s story of care at the end of life**

*Ron Paterson, 18 May 2015*

I’ve been asked to tell you a story of the care for a patient at the end of life. The patient is my friend, Judi Strid, who died on February 26<sup>th</sup> this year.

I acknowledge the presence at this forum of Judi’s mother, Cushla, and 3 of her 5 children: Kjersti, Bjorn and Bridgette, and of many colleagues and friends of Judi. Son Kurt in London and daughter Gretchen in Auckland are with us in spirit.

I’m telling Judi’s story because she asked me to. Judi was diagnosed with a brain tumour, a glioblastoma of the left frontal lobe, in November 2010. And with lymphoma, causing tumours in her face and bladder. That month, Judi appointed me her enduring power of attorney and made me promise to tell her story of care publicly.

This account is drawn partly from Judi’s own diary over four years, and partly from what I witnessed over the last four months of Judi’s life.

#### *Background*

I first met Judi in the early 1990s, and we became colleagues at the Health and Disability Commissioner’s office in 2004, when she was appointed as the independent Director of Advocacy. I learnt a great deal from Judi about advocacy and consumers’ rights – and we had a lot of fun along the way. Here we are photographed on “pink Friday” at HDC. Animals, and dressing up in bright colours (especially pink), were two of Judi’s great loves.

I somehow managed to get Judi to agree to have her photo in the HDC Annual Report in 2005. It never happened again.

Judi drew on a long background of consumer advocacy in her work as Director of Advocacy. She was a leader in the home birth and midwifery movements in the 1980s, and in the 1990s worked in women’s health to implement the recommendations of the Cartwright Report. Judi cared

deeply about informed choice, independent ethics committees, consumer engagement and evidence-based health care.

Judi loved promoting the Code of Rights. In her words:

“The Code ... could not be bettered as a framework for quality. It is consumer-focused and covers the dimensions of quality as well as consumer rights – with the focus on people getting the right advice, the right care, provided in the right manner, by the right person and the right outcome.”

Being Director of Advocacy was the dream job for Judi. She was a tireless champion of health and disability consumer advocacy and of consumers’ rights – especially for vulnerable consumers, including mental health consumers, deaf consumers, and residents of aged care facilities.

Judi also served as a consumer member of the national Quality Improvement Committee (the predecessor to the Health Quality and Safety Commission), where she championed consumer voice. She would have loved today’s Forum.

### *Judi’s story*

In receiving treatment for her tumours, Judi didn’t want anyone to know that she worked at HDC. Judi wanted to be a mystery shopper in the health system.

What Judi experienced wasn’t pretty. It certainly wasn’t patient-centred care. Her friends found it awful to hear about and wanted to intervene. But Judi told me, in May 2011 (6 months after her diagnosis):

“I just expect this and am pragmatic about it, so I don’t feel disheartened for myself, but [for] all the other patients who get similar treatment. This is why it is important to continue on as other patients do and not make a complaint, so we can use my story to really shake things up when the time is right.”

In this short talk, I can only draw out some of the themes from Judi’s 60,000 word health diary. They resonate with two quotes from Atul

Gawande: “People want information, control and guidance” and “the most reliable way to find out what people’s goals are is to ask them”.

### *Information*

Time after time, Judi didn’t get the information she wanted and needed. She was diagnosed with a brain tumour on November 7<sup>th</sup> 2010, after an ED admission and was prescribed a high dose of steroids, (Dexamethasone), with no explanation of the side effects.

Unsurprisingly, Judi wanted information about her tumour and prognosis. Yet, despite calls by her and her GP, Judi waited over 6 weeks for the first contact from Neurosurgery, a phone call from the Booking Clerk on December 23<sup>rd</sup>, to tell her she was booked for surgery on December 29<sup>th</sup>. During this time, Judi had several appointments with Haematology. She writes in mid December:

“Once again at the Haematology appointment I explain that the most important matter I wish to deal with relates to the brain tumour and the rest is just background. ... All my questions relate to the brain tumour yet I have not had an opportunity to ask them and get the answers I need.”

Judi *never* got told about her tumour before surgery. She saw the anaesthetist the morning of surgery, and learnt for the first time that she was to have a craniotomy with resection of the left frontal tumour.

Two weeks after surgery she sees “a registrar I had never seen before, who informed me very bluntly that I had an incurable brain tumour with a stage 4 malignancy, which he said is as bad as it gets and that I will die from it. When I asked about my prognosis and what the results meant he said that I had only months if I didn’t have treatment and that with treatment I may last 12 months, although I had probably seen my last Christmas.” “When I asked why I wasn’t able to see the surgeon to discuss the surgery [beforehand] he said organizing such an appointment would have just resulted in a further delay so they decided to go straight for the operation.”

So much for informed consent.

At every turn, Judi struggled to get information. She writes: “It has been a real struggle to get any written information (even when I know it exists) as it isn’t forthcoming when I ask for it. The only written information I was given was for the bone marrow biopsy at Auckland City Hospital – as it was about to be done, so I was reading it as the procedure was taking place.”

Only on reading her discharge summary does Judi learn that the drain she had in her head was due to a secondary diagnosis of hydrocephalus: “No one had explained this to me at all.”

Post surgery, Judi is told that she needs to have radiotherapy and on January 26<sup>th</sup> finally gets to see the radiation oncologist and receives lots of information – “I really appreciated his efforts”. She learns of the need for prophylactic antibiotics to protect against the risk of neutropenia and writes, “This is another example of how I have changed my views” after being given good information.

Accessing information from consumer support groups is left to chance. “No health professional has ever given me information about the Cancer Society ... 6 people with cancer [said to me] how disappointing it was discover well down the track about the wonderful services the Society provides.” Judi finds a leaflet in the waiting room, with information about radiation therapy orientation from the Cancer Society: “I was not told about this and as I am here for the simulation appointment it is too late to check it out.”

As her radiation treatment and chemotherapy proceeds during 2011, Judi again struggles to get information. In August, after seeing her consultant, she writes: “I didn’t get any information about the multi-disciplinary meeting yesterday, other than they are pleased with my progress, whatever that means. ... I have no idea what the future treatment plan is or what the overall plan is for managing my multiple cancers.” When she learns from the pharmacy (not her consultant) that she is being put on lower dose of chemo, Judi writes:

“I am fed up with people not being totally honest with me, deliberately misleading me with inappropriate comments designed to be reassuring and not providing me with all the information I need to know. Why they

would take it upon themselves to withhold information about me is quite unbelievable and very undermining. It is really affecting my level of trust in people and what I am being told. It feels patronizing and that I am not being taken seriously. This is the first time I feel quite low about my situation.”

Judi’s diary records numerous occasions of blood tests being taken without being told what they were for, and not being asked in advance about whether it was ok for a student or trainee to be present. (Judi was usually happy to agree, but wanted to be asked *before* the observer was present.) Basic rights, enshrined in law in New Zealand, but ignored in practice.

### *Control*

So many of Judi’s experiences were a world away from patient-centred care. The doctors, nurses and machines were in control. She writes: “It has been quite an insight to be told it is up to the doctor, not me – on several occasions! Unfortunately it appears that doctors have considerably more power than patients as they can just refuse to engage and refuse to carry out procedures if the patient is not compliant and doesn’t do as they are told. It has been a sorry revelation to see that we have a long way to go to achieve real and meaningful rights for consumers.”

The lack of control is vividly illustrated in Judi’s attempt to have regular lunchtime appointments for 30 sessions of radiotherapy at Auckland Hospital. She coins the expression “machine-centred care”. They are “unmoved by my need to know in advance as I am still working and need to know that I have times *around* midday.” Judi is told by the scheduler: “I need to talk to the treatment machine, [she] offers to put me through.”

Staff repeatedly tell Judi that there is a policy that patients cannot book their preferred times in advance; they are allocated each Friday on the basis of the availability of staff and the machines. Finally, after session 21, the team leader confesses that there is no policy, but disagrees when Judi suggests “it should be more flexible then, since it is just hospital practice”.

Three years later, in March 2014 when she needs more radiotherapy after tumour progression, Judi faces the same rigmarole about booking times. “Had to listen to the hospital policy crap all over again. I just lost it and said surely this practice isn’t still going on after 3 years! I told her there is no such policy and it is just historical practice that undermines patient choice. I [said] ‘this is the only thing in my life causing me stress, and she had the cheek to say ‘I am sorry you feel that way’.”

Judi records: “I saw the compliant culture in full form today: a woman come out with a mask in her hands – her final day of treatment – staff gushing over how well she had done. Then turn to me + say ‘This way please’. They have turned me into a difficult patient because I dared to ask for lunch times + challenged the Friday practice of issuing next week’s times.”

Other ways of controlling the patient are more subtle. Judi frequently records being “treated and spoken to like I was a child”. “Do you know why you are here? Where is your support person? On your own, tut, tut. Did you drive here yourself? (why would he think I would do that when anyone with a brain tumour is not permitted to drive?)”

#### *Co-ordination of care*

Right 4(5) of the Code has an internationally unique provision, “the right to co-operation among providers to ensure quality and continuity of services”. In effect, it is a legal right to proper care co-ordination.

Judi notes: “My expectation of co-ordinated care is when there is a designated person responsible for the oversight of my care to make sure that things happen when they are supposed to and someone I can go to for information, answers to my questions and advice.”

It doesn’t sound a lot to ask, but it never happened for Judi until the final months of her illness, when she was at home and refusing to go back to hospital.

The co-ordination of Judi’s care was woeful. It seems incredible that New Zealand’s leading tertiary hospital was unable to co-ordinate care between Neurosurgery, Radiation Oncology, Haematology and Radiology. Judi constantly turned up for appointments, only to be sent

away because necessary tests and procedures had not occurred. She was shuttled between the Grafton and Green Lane campuses. The departments seemed incapable of talking to each other. On one occasion Judi phones Haematology and after a lengthy delay manages to speak to someone, and asks whether the same place does bookings for the MRI and CT scans she needs: "How should I know? I don't work in Radiology". "Charming", notes Judi.

It's hard enough to imagine having a brain tumour and lymphoma and going through months of debilitating treatment. To be sent from pillar to post every time you're referred for a CT scan or an MRI or more radiation, and to wait for hours to be seen by consultants, is a cruel waste of the patient's time and energy.

As Judi says, "It is all such a shambles." "How hopeless it all is." "If only there was someone co-ordinating my care and overseeing things." "Patients are most definitely not central to any cancer service I have encountered."

In February 2014, Judi receives a notice about a conference called 'Optimising the patient experience'. "Wow, they need a reality check. ... If they just treated people nicely and had someone to coordinate their care, the service would be patient friendly at least."

#### *A lack of compassion*

In 2009, Judi had supported a national campaign to have "the right to be treated with compassion" added to the Code. As Commissioner, I did not support the change. I thought then (and still do) that compassion cannot be mandated by law, and needs to come from the heart of the healthcare provider. But callous conduct is unacceptable and is a breach of a patient's right to be treated with respect.

In 2011, Judi was admitted to hospital with pneumonia and very low haemoglobin, and received blood transfusions and intravenous antibiotics. Judi wakes in the middle of the night to hear another patient being put in the other bed in her room and helped to use the bathroom. She overhears the woman tell the nurse she has ESBL infection, whereupon the woman is moved to another room. Judi asks the nurse if the bathroom can be cleaned because she has a compromised immune

system. The nurse tells Judi off for listening to a personal conversation in breach of privacy! Soon after, the nurse arrives back with a rectal swab, “to check my infection status”. It felt “humiliating and like a punishment.”

This happened at Waitakere Hospital, the same hospital where a national Centre for Compassion in Healthcare was launched in 2007.

### *Listening to the patient*

Judi’s diary also records numerous instances of staff failing to listen to her, the patient. She describes encountering “very pleasant and well meaning people who don’t listen, don’t believe me and don’t take things seriously”. At her first admission at ED, when Judi says her pain level is 10, it is recorded as 4. Later, Judi tells the registrar: “I have a really high pain threshold and define a 10 as pain that is so intense as to be overwhelming and unbearable – which is what it was – and I was really taken aback that [you] didn’t believe me.” The registrar is very apologetic.

On another occasion, Judi is asked if she smokes and drinks and says “no”. (This one is funny to all of us who know what an avowed teetotaler Judi was.) A registrar records: “Says is a non-smoker and claims not to drink any significant amount of alcohol.” Judi surveys a wide group of colleagues, friends and clinicians. We agree that the record implies that the writer doubts whether Judi is telling the truth.

Judi believed that the voice of the patient is a powerful force for change. Her voice from her diary of 4 years’ dealing with the hospital system needs to prompt change. I’m pleased to say that senior people at Auckland and Waitemata district health boards have promised to work with me to learn from Judi’s experiences.

### *The final months*

Judi’s health began to deteriorate last year, starting with a series of seizures caused by tumour regrowth, leading to a bleed inside her tumour, and loss of the ability to speak. Judi had to stop work, and spent her final months at home, where she was determined to die, rather than at hospital or in a hospice.



As Judi's power of attorney, in a situation where she had lost the ability to speak – but not to understand or to nod or frown agreement or disagreement – it fell to me to co-ordinate her care and be present for nearly all the home visits by healthcare workers.

I saw first hand the problems Judi describes in her diary. It was disappointing for me to see that even hospice care providers are not immune from failing to listen and to offer help when needed.

The first time the hospice nurse and a social worker visited, they talked to Judi in loud voices, as if to a small child. "It's about the quality of life now, making the most of every day." Judi hadn't said a word for two weeks. Suddenly, she turned to the nurse and said, "You don't have to shout."

A month later (the first time Judi was willing to let the hospice nurse return), she asked Judi how she was doing. Because Judi was unable to respond verbally, the nurse turned to Judi's daughter Gretchen and said: "How do you think Mum's doing?" Judi frowned and looked upset. The nurse replied, "Well dear, this is a family situation." I told the nurse: "If you have a question for Judi, just ask Judi. She *can* express her wishes. If she wants us to answer for her, she will let us know". *Just ask Judi* – yet so often her care providers failed to do that.

By January, Judi was having falls and struggling with basic cares and taking her medication. We needed help, and with some difficulty persuaded Judi to allow me to find a healthcare assistant to come in to the home 8 hours each weekday.

I called the hospice for a recommendation of local services, explaining that I was Judi's EPOA. Unbelievably, they told me, "That's not our job." "Well how am I supposed to find a healthcare assistant?" "You need to look up the Yellow Pages." I was stunned. "No, I said, that's not acceptable. The family and I need your help. You're going to give me a recommendation". "No", she said again, "that's not my role". "Well my friend is a doctor at Mercy Hospice, and she tells me that it *is* the role of the hospice to recommend local healthcare assistance. I want you to email me some names within the next two hours". The hospice person was clearly very cross, but they did send an email with three

suggestions. I tried the first, Medacs, and within two days we had enlisted the care of a wonderful healthcare assistant, Sushma, who cared for Judi over her final weeks.

### *The art of great care*

One of Judi's initiatives as Director of Advocacy was to collect and publish stories of great care – to highlight exemplary care and encourage practitioners. Amidst all the uncoordinated and unsatisfactory care that Judi experienced, there were a few examples of wonderful care. In closing, let me relate some of the high points.

In March 2011, Judi writes:

“I found a great care doctor today. ... Dr Kim Han is a registrar working [in radiation oncology]. ... He invited me to contact him and come and see him if I have any issues before the next appointment, like nausea. That is pretty radical as I didn't think I would be allowed to do that. He had also read my notes so was familiar with my case (a refreshing change) and explained a whole lot of things that no one had told me before. ... He is really concerned with how my care has been either Haematology or Neurosurgery with no coordination between them and is going to follow this up. He was quite shocked when I told him I had to wait 2 months for surgery and 4 months til I was started on active treatment. ... My new friend Dr Han ... is a real gem and very patient-centred. If all staff behaved like him the service would be fantastic. Perhaps we can use him as a role model.”

Judi attributed her remarkable survival and ability to function so well for 4 years to intravenous infusions of high dose Vitamin C three times a week at the Integrated Health Options clinic in Remuera. Like many cancer patients having high dose Vitamin C, Judi initially chose not to tell her hospital doctors, because of the hostility to complementary therapies – notwithstanding emerging research that Vitamin C may improve the body's receptiveness to radiotherapy. The radiation oncologist tells Judi that, of all his patients, she is doing the best. Judi says she feels “fantastic”, and that “the medical profession needs to be challenged about their ‘weak research’ criticisms”. Judi describes the way the Clinic doctors and nurses monitor each person's status and well-being as “exceptional”.

In the final months, I witnessed the attentive listening and patience (in the face of communication difficulties) of clinic GP Dr Nicky Baillie, who came to the home to assess Judi, consulted by Skype, and carefully explained to Judi her illness progression and recommended medication changes. Dr Baillie regularly checked in with me, and always kept the hospital oncologists and the hospice informed about developments. Her care and compassion was a great support to Judi, the family and me.

By mid February, Judi was eating and drinking very little, and becoming less responsive. It was becoming harder to manage with just Sushma, the healthcare assistant, and visits from the hospice and district nurses. I was worried that Judi would not be able to stay at home. Knowing Judi as well as I did, I thought that hearing from an expert, a trusted oncologist might help. I called Judi's oncologist, Dr Richard Sullivan, and asked him for advice and whether he might be willing to Skype with Judi and me. "Ron", he said, "would you like me to come for a home visit?"

Richard spent 90 minutes with Judi and me, and daughters Gretchen & Bridgette. He explained the process of the body shutting down, and how the end was likely to come. There were a lot of tears that afternoon, but Judi beamed. She was the happier then, and in the days that followed (before she lost consciousness), than at any time in her final illness.

Back in November, I'd said to Judi – as I tried to get a better idea from her of how she wanted to be cared for in her final months – "I know this is hard to talk about." Once again, amazingly, Judi managed to speak: "No, it's not hard at all." So often it's us, the family and carers, who find it hard to confront the reality of dying.

Judi's honesty and directness was a strong feature of her personality, and it was never more evident than in her approach to her illness and dying. She anticipated the need for an enduring power of attorney; and while she was still well, she had given me clear directions. For someone like me, who knew all the theory about powers of attorney and advance care planning, these were powerful practical lessons.

Nearer the end, it was sometimes really hard to know what to do, and to try and work out Judi's wishes. I struggled too. But I came to realize how

important it was for Judi to retain some autonomy as her world was shrinking, and her ability to comprehend was fluctuating. Somehow, we found a way.

My friend Dr Mary Seddon emailed me on Saturday about this talk. She knew Judi well. Mary said: "I was thinking about your talk. Palliative care is important for the patient but equally if not more important for the family. They are the ones left with the memories of a good or bad death. Think of the time you had with your Dad and his gentle death. So maybe you can reflect on the effect that Judi's end of life care had on her and her family & friends."

Judi had a wonderful care team at the end: daughters Bridgette and Gretchen and healthcare assistant Sushma. Sushma taught us all. She said to me one day, "I love Judi. In India we say, 'she is mixed spice'. A little bit spicy, a little bit sweet."

Judi died, peacefully at home, as she wanted. She taught us so much. Our memories are good ones.