March, 2019

Janet's story – a matter of time.

Outwardly many people living with terminal cancer can appear to be living an ordinary, 'normal' life.

Janet Cohen resembles lots of other 'outdoorsy', 60-something women.

On the inside however, Janet rarely feels 'normal'. Terminal lung cancer has changed the way she lives every day and has radically altered her perception of the concepts of 'now' and 'the future'.

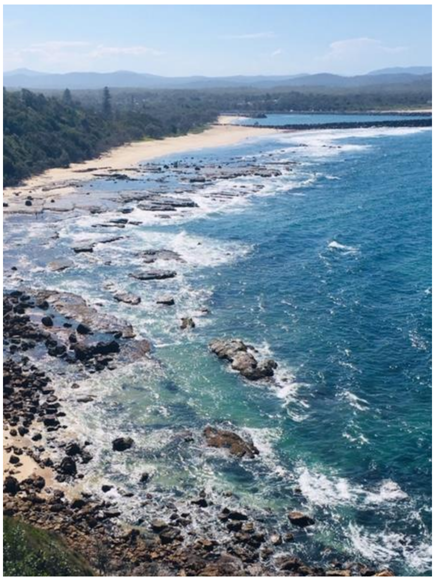
Enveloped by a regime of tests, scans and treatment, Janet has turned to writing and other creative outlets to deal with the frustrations and fears that have found their way into her life, transforming themselves into questions that demand answers.

She has agreed to share some of her written work[1] with others via the Our Stories Project.

This piece tells another side to Janet's life and death story.

A matter of time

by Janet Cohen



Unless I told you and you were really able to listen, you'd never know that I'm struggling to live with terminal cancer. On the surface, I'm just like any of the retirees enjoying the good life amongst the bush and beach of Camden Head, on the NSW Mid North Coast.

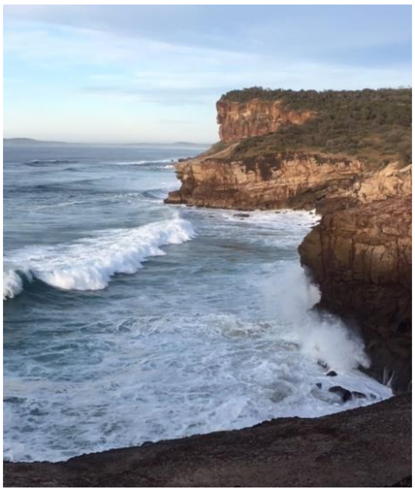
I walk in Kattang Nature Reserve, swim at Pilot Beach, potter in the garden. I enjoy the embrace of community life, and relish friend's visits to our beachside haven.

When we can, my partner Glenn and I disappear in our camper, the 'Tardis', sometimes just along the coast to Crowdy Bay National Park, north to Trial Bay or out west to the big skies of the Warrumbungles and the Pilliga. This summer we hope to head south on our annual pilgrimage to Tasmania. To all outward appearances we're living the good life.

I've retired from fulfilling, creative work at Sea Acres Rainforest Centre, with the NSW National Parks and Wildlife Service.

At my retirement party Uncle Bill O'Brien, a Birpai elder and four Aboriginal tour guides presented me with a large painting they had created symbolising how I helped them connect with and share their culture.

Principal artist Steven Donovan depicts me as a white-limbed gum nurturing the team. I'm satisfied with a fortunate working life of more than 30 years in community development, the arts and environment.



With more free time, I've started writing stories, joined book and philosophy discussion groups, reconnected with old friends and started painting again. As a sporadic meditator I appreciate the space for a less driven, more contemplative, approach to life.

On the surface, I look just like everyone else, but I don't feel like everyone else. I feel singled out, and even though I know it isn't rational, I feel I'm being punished for something I didn't do.

In 2013, just before my 60th birthday I was diagnosed with lung cancer which swept into my life like a gale force storm.

In 2015 the cancer recurred and as if overnight went from Stage 1 to Stage 4, terminal. Since then my focus has been how to stay afloat in this vast ocean out of sight of land, sailing into thick fog with few reliable charts.

Cancer's storm clouds cast a pall across each day, reaching into the past and projecting into the future.

Cancer's storm clouds cast a pall across each day, reaching into the past and projecting into the future.

My thoughts frequently chart a familiar course through a rocky shoal of questions that have no answers

Why did this have to happen? If only I'd not worked so hard, taken things more slowly, looked after myself better. Might things have been different?

My life is lived in what feels like 3 month reprieves between CT scans and although logic tells me I need this and am lucky to have it, I dread stepping back onto the medical conveyor. Lying alone in the scanning tube a needle inserted into my vein, I feel the warm, flooding sensation as the contrast medium is injected, hear a voice telling me to "breathe in and hold your breath…breathe". Then the "scan-xiety" while waiting for results. My kind GP frequently rings me, lessening my torment, but I fear every phone call.

Sometimes I just turn the answering machine down and switch the mobile off. If they can't reach me maybe this will all just go away. Waiting with other patients at the Mid North Coast Cancer Institute, my eyes dart to the consulting room door, trying to gauge the look on the oncologist's face as he calls my name.

What will this scan reveal? Will I be at the edge of the cliff or standing way back? In a few moments will I dance out of the building or will I feel the earth suddenly drop away under my feet? When does it get better?

Right here, right now is probably as good as it's going to get.

I'm sad that I probably won't be around to enjoy many 'freeform' leisure years with Glenn, and it isn't very generous of me, but I envy those who can enjoy life with their partners without the threat of a terminal illness forming the backdrop to their days. Do they know how lucky they are?

I'm cranky. Cranky with those who can make holiday plans not plagued by uncertainty. Cranky with people who've reached a ripe old age and whinge about minor things like a faulty NBN connection or a broken down washing machine. Talk about First World problems! I'm cranky with people who treat their bodies with disrespect, people who stack their supermarket trolleys high with sugary junk food.

I'm furious with smokers. I want to shake them by the shoulders and roar into their faces STOP!

I'm especially cranky with people who try to pinpoint why I have lung cancer.

"Were you a smoker"? Does anyone ever ask someone with breast cancer why they got it?

It used to comfort me to think that everything happens for a reason. Now I find the thought offensive.

It used to comfort me to think that everything happens for a reason. Now I find the thought offensive.

No one knows why I got lung cancer, and as much as I may want a reason or something to blame and for life to be in my control, it all feels quite random.

Sometimes big waves just rise up from even in the calmest of seas.

It's difficult being the only person in my peer group who knows she has a terminal illness. In our death-denying culture people find it hard to accept the simple fact that I am terminally ill and will die sooner, rather than later. Lack of acceptance creates a mine field of denial, through which I feel I must tip-toe to avoid activating other's hair-trigger, death-averse sensibilities. It's as demanding reacting to other people's 'stuff' about illness and death as dealing with my own.

"You have to stay positive. It's crucial for people with cancer to have a positive outlook" - oh … so you're saying that if the disease progresses it will be because I wasn't positive enough?

"You're not the only one you know…we're ALL going to die" - yes I had kind of noticed that, but YOUR death sentence hasn't been handed down yet!

"Knowing you, you'll probably outlive all of us. They're coming up with new treatments all the time" - yes, I do have hope, but the new treatments have limitations with my type of cancer. It's really true, the devil is most definitely in the details!

"Oh, so it's been 5 years since you were diagnosed. Are you still in remission"?

"Have you tried acupuncture, cannabis oil, black salve, Jesus, mindfulness meditation, a Ketogenic diet?"

"How much sugar do you eat? You know that cancer feeds on sugar."

My counsellor says I can't expect people to respond skilfully or appropriately when confronted with terminal illness or death, but I want someone to simply say "I'm so sorry this is happening. How are you coping? Are you OK? Is there anything I can do to help?"

Instead we try to fix it, make it better and if this fails, get as far away from it as possible, anything but own and face our distress about death and the impermanent nature of life.

How do I deal with the daily physical, emotional and spiritual challenges presented by this illness and after all is it such a big deal? I'm not the only one. What's all the carry on?

I try to go with acceptance and dignity into a turbulent ocean, riding out the waves of anger, fear and sadness that occasionally threaten to capsize my little boat. I try to maintain the strength, flexibility and awareness needed to keep my balance and remain upright. I seek the sheltered coves, look for any deep anchorage and enjoy the calm patches.

I try to chart a course through the treacherous reefs ahead. I activate plans to die well. We all want a 'good death' but now I am actively planning for it and I'm lucky to have the resources to be able to steer this course although it will take me outside Australia. I'm sure one day our governments will give Australians the right to end their lives with dignity.

I try to laugh about it all, this sweet and sour, pleasure and pain crazy journey we call life.

I try to feel gratitude for the years behind, the delights and challenges in each day and the unknown time ahead, but I know that beyond any skilful manoeuvres I pull off, beyond any plans I think I've put in place, that the crest of this great wave will eventually spill when it reaches its peak, as it will for all of us.

It's really just a matter of time.

Thank you for sharing Janet.

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[1] Other stories written by Janet Cohen and included in the "Our Stores" Project include "Rediscovering myself" and "Advice from a wise friend".

More about Janet

Janet Cohen is a passionate advocate for protecting the natural environment and for community the arts and culture. She is perhaps best known for her work with the National Parks and Wildlife Service, redeveloping and managing Sea Acres Rainforest Centre in Port Macquarie NSW, a unique visitor centre featuring rare coastal subtropical and littoral rainforest and Aboriginal cultural programs.

Not one to shy away from a challenge, Janet and her partner Glenn spent three months as volunteer caretakers on remote Deal Island, in Bass Strait, where they grew veggies in howling gales, survived the wild Bass Strait weather and worked to conserve the island's natural and cultural heritage. Janet and Glenn love the bush and have spent time backpacking in remote areas.

Janet has also been active with local community projects including Friends of Kattang Nature Reserve, Camden Haven Protection Society and Camden Head Pilot Station.

Janet has been vocal in her support of the introduction of Voluntary Assisted Dying in NSW and will continue to share her story about living with a terminal illness to add to the call for legislative change on this issue.

Janet says the "Our Stories" project has given her the opportunity to reflect on and validate her experience of cancer and to connect with fellow travellers who are on or have gone through the cancer "journey".

Janet Cohen with partner Glenn

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CALL FOR COMPASSION: Janet Cohen has spoken out in support of the Voluntary Assisted Dying Bill 2017.

Political plea

BY **LISA TISDELL**

DYING with Dignity advocate Janet Cohen has a clear message for politicians: make the compassionate choice.

Janet has added her voice in support of the Voluntary Assisted Dying Bill 2017.

"Make the change, vote with 75 per cent of Australians who want this legislation introduced for terminally ill people," Janet said to the decision-makers.

Janet has shared her experience to add to the call for political change.

The Camden Haven resident had surgery, which appeared to be successful, after a cancer diagnosis in 2013.

The cancer came back in 2015. It is not curable but Janet is being treated with life-extending medication.

"That's been an everyday miracle really," she said about the medication.

The cancer journey is by no means straightforward.

There is loss – a loss of control, loss of choice and loss of options, she says.

"The final loss is that loss of independence and dignity that can happen at the end of life," Janet said.

"I am not afraid of death but I am afraid of pain, and I am afraid of suffering and very concerned about that.

"I don't want to die a protracted, painful death where I suffer, and unacceptably suffer."

A 2016 report, which covered 106 Australian palliative care services, showed 22 to 25 per cent of patients died in moderate to severe pain.

MidNorth Coast Dying with Dignity NSW convener Annie Quadroy has called on MPs to recognise they have a strong political mandate given the successive assisted dying opinion poll results.

Janet echoes that position.

"Throughout your life the system supports you - our political system, our social system supports you to make informed choices," she said.

"But at the end of life suddenly you don't have any choice and that's just not right."

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“Our Stories” Project – empowering people to share their stories.

To see read more stories, go to www.hastingscancertrust.org.au/our-stories
Contact: OurStoriesProject1@gmail.com

This story was written by Janet Cohen and forms part of the “Our Stories” Project, which was funded by a grant from The Hastings Cancer Trust.
The Hastings Cancer Trust is a local, not-for-profit organisation that supports local cancer services via their annual grants program. For more information go to www.hastingscancertrust.org.au.