



a survivor's story

From the Australian Cancer Survivorship Centre



Linnet Hunter's story, as told by Meg Rynderman, a consumer representative for the Australian Cancer Survivorship Centre

February 2016

'It's not selfish - it's self-care'

Linnet Hunter

She is a writer, a facilitator and a coach, teaching and assisting others. Her working life revolves around giving and helping people. The tables were turned when, a year ago, at age 58, she was diagnosed with cervical cancer.

Linnet Hunter told me her story when we met recently at Peter MacCallum Cancer Centre.

"As a coach who spends quite a bit of time listening and helping others, wanting to help, always being thoughtful, [a] loving, giving, nurturing sort of person – I thought 'I'm going to really have to learn to ask for help and accept it'."

That learning began when Linnet, who lives in rural Victoria 130 kilometres from Melbourne, started to experience what she thought were menopausal symptoms: increasing incontinence, loss of libido, irregular bleeding and tiredness. These symptoms would ordinarily be of minor concern. However in combination with an irregular pap smear, they resulted in a hasty referral to a gynaecologist. Examination revealed a 5 cm

tumour on the cervix. Linnet was diagnosed with squamous cell carcinoma of cervix (FIGO stage 2b).

"The gynaecologist referred me immediately to the Royal Women's for the MRI and the CT scan and the Royal Women's then said, 'You'll be treated at Peter MacCallum'. They just sent me straight to the gynaecological oncology department."

A treatment plan was developed, which involved five weeks of daily radiotherapy and four internal brachytherapy procedures under anaesthetic followed by 12 weeks of chemotherapy.

Even before the full diagnosis, Linnet was contacted by a Cancer Link nurse from Colac Area Health.

"She was the first person who got in touch with me. She's just been there for me the entire way. She's absolutely extraordinarily helpful. Also, because she's a nurse, unlike ... support groups you could ask her anything and she knew or she'd find out. She let me know that I could get home help to come and do the housework, and she

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arranged money to help with the electricity bill, she told me about the holiday houses that cancer patients can access. She knew all about every kind of service."

Living in a small, rural community with her partner, her children grown and living far away, Linnet appreciated the warmth of friendship.

"I found the reaction from most people was that they wanted to see me immediately. Even though they might have seen me the week before and I was no different, they needed to see me immediately. It's interesting because, whether the actual diagnosis or the prognosis is quite positive or not, the word ['cancer'] has a fatal ring to it and people needed to see me. My interpretation is that they felt their own mortality.

"But the deep friendships that I have; people absolutely just came out – wrote me cards, rang me up, came and visited me, told me face to face that they loved me, which was such a gift. A lot of people say this: 'You never feel so cherished as when you have cancer'."

She responded to the needs of her friends and family in her own unique manner.

"I invited my friends who were on Facebook to join me on that and it ended up eventually being 25 women on a private Facebook group and they were extraordinary. It was called the Circle of Healing and it was not just for me, it was for anybody who needed any healing. They organised a meditation on a Tuesday night so that everyone, no matter where they were in

the world, would meditate on my health at the same time."

Along with her Facebook group, Linnet created a series of email newsletters, which she produced regularly, when she was able.

"I called the whole thing Project C and then every month I would give them an update of just where I was in the process. I took photos and selfies all the way ... People really responded to that in quite a special way. They would say, 'Look, we've had a lot of friends go through cancer, we never really knew what was happening and we never really knew whether we should contact them or what stage they were up to' ... If it was during chemo, when I was completely 'out' on the couch and able to totter to the toilet and the shower and that was about it, I could let them know and say, 'If you haven't heard from me and I don't answer the phone, I'm just sleeping, I'll be back with you in a month' – and that was good."

A prolonged treatment program involved financial stress, dislocation of home and business life. Self-employed, Linnet gave up her business during this time and travelled regularly to and from Melbourne, two hours by train or car.

"[My partner] stayed in Birregurra and kept working when I was having radiotherapy and he'd come up and visit me as often as he could and I'd go home for the weekend."

Linnet spent time in the Peter Mac Apartments, adjacent to the hospital. Here her partner or her daughters, when they visited from





Linnet and Penny.

England, could stay with her.

She spoke fondly of the assistance and support she received from her partner, her family and a dear friend, Penny, who renovated part of her home in Melbourne to create a space for Linnet.

"I can't tell you what Penny has done for me – she drove me here and back all the time, she works part time so she was able to do this for me and I accepted that gift of loving friendship. I lived with her for about four weeks ... She wanted me to have my own space, so I could go up there and have a sleep, didn't need to talk to anyone. It was an amazing thing, it was such a healing restful gorgeous space."

Having studied a graduate diploma in coaching, focusing in part on emotional learning, Linnet turned to her teacher and her colleagues. They held lengthy conversations around how she was feeling and coping.

"The conversations that we had ... really was the most powerful and useful thing that happened. I didn't spend very much time asking, 'Why me?' I just thought, 'Well, this has happened for a reason'. I do believe everything happens for a reason; whatever it is I'm going to have to learn out of this."

She reflected on how she had managed during treatment and recovery.

"Observing when I got right into that terrible pain, how hard it was to get outside the bodily experience and do anything. It was so all-consuming, you couldn't think of anything else, it was totally horrible and you didn't want to be there.

"The other main emotion that I felt was frustration. I felt so frustrated that I couldn't do things. The frustration level was extraordinary. It's like being [age] 85 before your time and you're not able to get

down the stairs. Like that little walk to the front gate which used to be easy and you look back and think, 'Oh my God, I can't believe I've done it'."

She commented on the kindness and consideration she experienced from her treatment team and the staff she encountered.

"There's a lot of suffering going on and somehow they don't hold themselves apart from it but neither do they buy into it. They're not ridiculously cheerful, but they're always smiling and that is so ... It's like being on a sea of calm. It's so supportive to walk into that mood and that sort of atmosphere I suppose.

"They always said, 'Well, everyone reacts differently. What's your reaction? Tell us about what you've noticed' and then they deal with that. And that was so wonderful because I don't want to get into an 'us and them' thing; it was a team – they were on my side, we were



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all working on it together and that included me every step of the way.”

Patients are often asked to take part in clinical trials during and following their cancer treatment. Linnet took advantage of a number of clinical trials offered to her.

She spoke with appreciation about the PeNTAGOn psychosocial trial, a nurse and peer-led support program to assist women in gynaecological oncology receiving curative radiotherapy.

“I had a mentor and face-to-face and phone support with Nicole [a nurse co-ordinator]. I saw Nicole every couple of weeks, either in person or on the phone, for an hour, to just check in where I was going, how I was getting on with things, what things were bothering me most and really very much like a counselling session. And then I also had my mentor who'd ring up every two to three weeks, just checking in with me and talking through any questions, sharing what she'd been through. Cervical cancer, thank goodness, is fairly rare – more rare than some cancers, so it was nice to talk to someone who'd been in the same boat.”

Meditation, mindfulness, yoga, eating well and keeping up her

fitness were all things Linnet aimed for when she was diagnosed. She found her intention challenged by her body's reaction to her treatment.

“I had one doctor and I was saying to her, ‘I know I'm supposed to be keeping fit while I'm on chemo, but I just don't seem to be able to’. And she said, ‘Do you put your running shoes on and that's all you can do?’ and I went, ‘Yep’ and she goes, ‘Well, that's all you can do and that's enough’.”

Post-treatment, to help restore her body and mind, Linnet has taken advantage of two services offered to people post cancer treatment.

“I knew I was supposed to get back to walking and do my yoga [but] I just couldn't get into it. I'd put on 10 kilos with the steroids and me eating toast, basically carbs, for three months. My clothes didn't fit and I felt uncomfortable.” Linnet signed up for a Cancer Council Healthy Living after Cancer course. When she told the course coordinators that she was having a tough time, they suggested intimacy counselling at the Royal Women's Hospital, which Linnet has found to be “a wonderful service, extraordinarily helpful”.

Linnet's personal situation has undergone a major shift since her “all clear”. She is re-organising her life and “devoting myself to wellness”.

She is planning to travel to the UK and is working to revamp her business to enable a lengthy stay with her daughters.

She refers to herself as a graduate from “that school of learning that's so extreme”, one where she learned that focusing on herself “isn't selfish, it is just self-care”.

Further information and support:

Cancer Council Victoria:

<http://www.cancervic.org.au/how-we-can-help/healthy-living-after-cancer>

<http://www.cancervic.org.au/how-we-can-help/phone-support/intimacy-counselling>

Royal Women's Hospital

<https://www.thewomens.org.au/health-professionals/sexual-reproductive-health/sexual-counselling-clinic/>

Victorian Integrated Cancer Services:

<https://www2.health.vic.gov.au/about/health-strategies/cancer-care/integrated-cancer-services>

BreaCan:

<http://breacan.org.au/>

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A Richard Pratt Legacy



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