



# a survivor's story



From the Australian Cancer Survivorship Centre

## Meg Rynderman



This is the content of a speech given by Meg Rynderman, ACSC volunteer, at the Peter Mac Grand Round presentation on 1st October 2012. Meg describes her cancer survivorship journey.

### 1993

**Nodular sclerosing Hodgkins - lymphoma stage 2A**

**Aggressive mantle radiotherapy – 20 sessions**

*You're so lucky said well-meaning friends conducting their own well intentioned enquiries –*

*Hodgkin's is the best cancer to have!  
No chemo – that's the worst!*

### 1994/1995

**Radiation pneumonitis  
multiple admissions**

**Radiation pericarditis**

**Chest cracked for a cardiac biopsy**

**Radiation fibromyalgia**

### 2001

**Recurrent Hodgkin lymphoma  
chemotherapy – 6 cycles**

### 2004

**Recurrent aggressive  
Hodgkin lymphoma**

**Autologous stem  
cell transplant**

My name is Meg Rynderman, I am 62 years old, a wife, mother and grandmother and a volunteer with the Survivorship Centre.

Some time ago, when I put together these words for the first time for the launch of the Centre, I went on to say that I had been symptom free for six years and considered myself truly lucky to be a survivor.

How quickly things change - at the end of 2010 I found a lump in my right breast and rapidly experienced a whole new set of tests and diagnoses confirming hormone positive breast cancer. A new random cancer occurrence or one related to previous mantle radiotherapy? It doesn't really matter which.

My earlier cancers made treatment decisions complicated – radiotherapy was contra-indicated and chemotherapy non-preferred. My doctors and I came up with a treatment plan, bilateral mastectomy and reconstruction followed by anti-hormone therapy.

And my luck continued to run – pathology results showed evidence of cancer in both breasts, previous radiotherapy rendered my tissues less elastic than they might have been and promoted the production of fibrotic tissue.

The reconstruction process and beyond has proved challenging and I have needed to advocate for myself to find answers and alternatives.

Slowly, I am reclaiming my life. The goal posts have shifted once more – I am changed physically and psychologically, and again I survive.

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Over the years I have been able to draw strength from the unconditional love of my family and the remarkable support network they and my friends create around me whenever I require it – I have never had to do this alone and have come to recognise how vital those relationships are to my very being, to that survival.

I might, I think, have chosen a gentler and somewhat less brutal journey for myself. But, regardless of the means, the end has found me enriched.

People speak to and of individuals dealing with major illness in terms smacking of hyperbole – battles are fought, won or lost, individuals are described as heroes; struggling, suffering, afflicted.

Survivorship and the incorporation of the losses that accompany it is about all this and so much more; it is about the cancer journey – the doctors' visits, the biopsies, the scans, the chemo, the radiotherapy, and the surgeries; but it is also about the rest of your life. The slow, painful return to health, the follow-ups, the odd and unexplained side effects and ongoing concern over the tiniest aches and pains. The impact on partners, carers, family and friends - their concerns when a new symptom or potential issue emerges, the emotion surrounding annual check-ups.

The language around battles and bravery surrounds survivorship as it surrounds cancer - *she fought bravely... after a long battle... an ongoing struggle...*

I am more comfortable with the metaphor of the fairground.

Not the sweetness and innocence of fairy floss and balloons; my cancer treatment experience was like a roller coaster – unexpected highs and lows, slow painful climbs, rapid descents with no guarantee of what was to present around the next bend.

There were visits to the house of horrors. A sign flashed ominously above the door - leave behind all you knew before, you are now entering the *new normal*. Unexpected side effects transformed the body as if one was looking into a distorting mirror. Recurrences, fears, the

ground was unsteady, I was never sure when it would give way.

Along the way there were those visitors who could not remain there. They tried all the rides, experimented with everything that was on offer, but slipped away without fanfare. So many of us started our visit together; sadly we continue it without them.

And survivorship, now that's a ticket to the merry-go-round. Oncologists finish treatment and follow-ups and wave you goodbye to get on with the rest of your life. GP's watch nervously, never sure whether symptoms are related, should be tested or scanned, quietly suspecting something sinister; families observe, worried that you might fall off the pretty merry-go-round horse of health.

Survivorship is indeed all this, but it's about something even more fundamental – survivorship is about re-starting your life. Survivorship is about understanding that this immediate threat to your mortality has passed. It's about accepting the changes, understanding the new normal, incorporating the scars, the loss of function, and the limits and about waking up each morning to face a new day.

My cancer journey has introduced me to various cancer streams, testing, treatments and new and remarkable technologies – I have experienced radiotherapy, chemotherapy, transplant, surgery, and hormone therapy. I have met and interacted with a myriad of doctors, nurses, support staff, technicians and more. Remarkable human beings whose vocation of choice is to support those diagnosed with cancer.

When it began, almost 20 years ago, I climbed onto the roller coaster alone. My treatment was effected by wonderful, caring professionals; there were no support systems in place, no one to speak to aside from the oncology nurses or doctors, no linking with others' undergoing similar experiences.

But there were, well remembered, the kindnesses of the professionals I encountered – the nurses and technicians who helped allay my terrors as I lay waiting to be measured and

marked for radiotherapy, the generosity of those who explained procedures and the workings of machinery to my frightened children as they watched me undergo treatment.

Side effects of treatment are something you never fully consider as a newly diagnosed cancer patient. Your oncologist might outline the more obvious side effects – hair loss, vomiting, burning, loss of taste and might even touch on some of the common late effects.

Newly diagnosed, my capacity for comprehending and retaining these was negligible. My overarching philosophy, throughout my entire cancer journey has been to deal with one diagnosis, one treatment at a time – not to project too far forward and waste energy on the what-ifs.

Aggressive mantle radiation completed I dealt with my burned skin – sweat glands and underarm hair that have never become viable again, with my hair loss and fatigue. But when, over a period of 2 years, I found myself experiencing multiple post radiation diagnoses and hospitalisations – side effects became a glaring reality. There, I was always the cancer patient - nurses unsure of how to deal with me in general or cardiac wards.

My oncologist was excited when I presented with pins and needles in my legs as I lowered my chin to my chest – Lhermitte's phenomenon, he went scurrying for the textbooks to show me.

Slowly the side effects of radiotherapy passed into memory, I had recurrences and new treatment side effects to deal with. Somewhere in the dim recesses of my mind I vaguely remembered the catalogue of late effects - thyroid, heart, breast. It seems with this latest cancer that I may have started to deal with that list.

Over the years, the situation for patients and survivors has improved, diagnosis and treatments have become more accurate, machines more sophisticated, drugs more effective. Help-lines and support groups put people in touch with one another, information is more readily available.

Recently I have experienced some of those changes – breast surgeons incorporate the services of breast care nurses into their practices, test results



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are communicated more effectively, discussions around treatments and outcomes are full and frank. There are active cancer specific support groups available, genetic testing and counseling where needed, links to other survivors and centres for survivors to obtain information and exchange stories.

But some things have not changed.

I have been made to feel an unwelcome complainant inconveniently presenting atypical symptoms or unexpected levels of pain or discomfort. And have felt unheard and patronised by doctors and support staff that appear to be concentrating on outcomes rather than listening to and acknowledging my fears and concerns.

I am a user of the private system. Supportive care screening is not a tool which has been made familiar to me or that I have been offered. I have needed to advocate for myself to obtain

referrals for follow up services such as psychology, lymphoedema and scar tissue physiotherapy and acupuncture.

Anecdotally I have been made aware of women in both the public and the private systems, not aware that they don't have to spend the rest of their lives unable to raise their arms following breast surgery. Others have overheard conversations in doctor's waiting rooms or found their way to allied health professionals with the assistance of other patients. These stories, I know, are not limited to breast cancer - patients from most cancer streams are aware of those that have fallen through the cracks of treatment and supportive care.

Cancer is still treated as a one-off incident, rather than a whole of life health issue like heart disease, diabetes or asthma. Treatment is effected, follow-ups monitored over several years and the episode considered closed. Patients are

returned to GP's with no record of their treatment or suggestions for follow-up care or appropriate referral regime.

I am grateful that the fates have conspired to allow me to volunteer with the Cancer Council's Cancer Connect program and with the Survivorship Centre and to work in some small way towards change and the ongoing supportive care of survivors.

Through Cancer Connect I have the privilege of being able to directly support others experiencing cancer diagnoses, treatments and their side effects. To lend my time, my ear, my own lived experience to answer their questions and help to allay their fears. Not by offering treatment options or comment on their diagnosis or medication, but to be able to listen to their concerns and their anxieties, to understand the 2am what ifs, to offer hope, to affirm that having once stood in their shoes I am still here.



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My own use and experience of the system has shown me gaps and cracks where patients, during and post treatment can feel lost or overlooked.

My work with the Survivorship Centre has informed me of new studies and initiatives at Peter Mac to try to fill those gaps and smooth the cancer journey and has introduced me to up to date information, easily accessible and available to both survivors and professionals.

In the same way that a cardiac care plan assists patients post heart attack or other cardiac episode - Cancer Care Plans are currently under development and trial.

As a survivor it is my hope that these Care Plans would outline diagnosis, fully explain treatment, list drugs administered along with explanations of side effects, possible late effects and directions as to whom to contact should they occur. Follow ups would be scheduled and monitored.

Details of allied health professionals – psychologist, physiotherapist, mental

health social worker, etc might also be included. Issues of case co-ordination, management and advocacy might be discussed openly in pursuit of a holistic bio-psycho-social model.

Initiatives are also underway involving health professionals to improve their knowledge and understanding of survivorship.

It is my hope that medical and nursing educators will come to recognise that cancer diagnosis and treatments have far reaching implications, requiring sensitivity, empathy and understanding often extending well beyond the treatment oncologist and surgeon and will incorporate that recognition into their training of all health professionals.

That health professionals will come to accept and acknowledge the differing needs and requirements of each individual patient, focusing on their holistic needs, not just their medical requirements. They will listen to their patients, hearing their concerns,

focusing on each person rather than their own professionally accepted idea of practice and outcomes.

That GP's will be educated and informed as to the most effective way of dealing with the survivors returned to their care.

And most importantly, that cancer will finally be treated as a whole of life health issue with survivors supported, not just through the critical stages of diagnosis and treatment, but for the remainder of their lives.

My survivorship is informed by my own survival and my experiences. I am indeed lucky to have been given the opportunity to find my voice as a survivor - hopefully to use that voice to assist other survivors find theirs and help to change the system to make their ride on the roller coaster a smoother one than mine has been.

**Meg Rynderman**

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## Australian Cancer Survivorship Centre

A Richard Pratt Legacy



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