



# A survivor's story

From the Australian Cancer Survivorship Centre

## 10 Years On – My Story Retold

**Meg Rynderman is a consumer representative with the Australian Cancer Survivorship Centre (ACSC), who has interviewed many survivors and published their stories on our web pages.**

**We warmly thank Meg for her work with us over the past 10 years.**

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I told my story for the first time at the launch of the ACSC at Peter MacCallum in 2010. I commented that friends had told me I was “so lucky”, “lucky that Hodgkin’s was the best cancer to have”, “lucky that radiation was so much better than chemo”.

Ten years on, the ACSC is celebrating a significant anniversary, reflecting on important achievements in the provision of information, education, support and tools to aid both survivors and healthcare professionals.

During that time I have seen the introduction of survivorship care plans, supportive care screening, needs assessments, healthy lifestyle guidelines, optimal care pathways, patient-centred care, self-management, shared care and a myriad of new diagnostic and treatment protocols.

Mine has been a cancer journey spanning more than 25 years, starting with a diagnosis of Hodgkin lymphoma, followed with increasing severity by two recurrences and a breast cancer diagnosis requiring a double mastectomy and reconstruction, and recently a recognition of something anecdotally referred to as “breast implant illness”.

Tests, biopsies, scans, aggressive mantle radiotherapy, high-dose chemotherapy, apheresis, stem cell transplant, hormone therapy and surgery – each of them has promoted

a kaleidoscope of reactions and side effects, often requiring hospitalisation.

My companions: a formidable array of chemical compounds with intimidating names, usually accompanied by gloved, gowned and bespectacled attendants.

**Today, I am well and cancer free.**

Invariably, a lingering headache, a persistent rash or any ailment not easily diagnosed will lead to a regimen of cautious testing with unspoken concern around recurrence or secondaries.

Ongoing side effects and late effects are things that are skated over, never considered in the immediacy of diagnoses, treatments and surgeries.

A mental scan of my body would reveal the following: weariness as a

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constant companion, menopause for the third time with all of its attendant side effects, vaginal dryness making intimacy painful, nightly violent cramps in feet and calves, peripheral neuropathy and post-mastectomy discomfort. I experience loss of breath walking up hills, oesophageal scar tissue causing violent coughing, and morning showers taking longer to warm bones and ease my body's stiffness. All of this covers the physical and doesn't take into account the emotional and psychological – my libido has disappeared, placing an enormous strain on my partner and me.

I live much more in the moment, take each day as it comes, make the most of it and don't project too far into the future. I am more self-contained and comfortable in my own space.

Most of this is related to my various cancers and their side effects; some, though, I'm sure, is due to the fact that I'm now 70 and feeling my age.

I am vigilant with my screening checks and I'm SunSmart. I am aware of and listen to my body; I use yoga breathing to help me when I walk up hills, I go to Pilates, walk regularly, eat healthy food and, when I remember, meditate or do my relaxation exercises. That is my 'new normal' and I'll take it any day rather than the alternative.

My husband and I ran a family business, staff and deadlines needed attention; he held it together – supporting both me and our children, "wiping my fevered brow" as he jokingly referred to it, fielding the phone calls and often intrusive enquiries, covering for me when I was too sick to be at work.

His life has changed along with mine. Not only has he supported me throughout my lengthy journey

but has also been impacted by my treatments and side effects, my changes both physical and psychological; all the while quietly worried about those unmentionable "what ifs"; concerned if I'm pale or tired or wince when I stand up or move.

**Over the years, people have directed their concerned questions about me to him; rarely has anyone asked how he is feeling, or whether he might need some support. His life has changed in equal measure.**

My three children, now parents themselves, were so young when it all began; the impact on every aspect of their lives has been enormous. They have shared with me their unconditional love and support – ensuring, through the laughter and the tears, through the normality

of everyday life, that I was able to maintain a sense of perspective. They helped me not to be overwhelmed, but to retain a constant focus on what was important in my life.

Each time, family and friends stepped in with care and assistance. How lucky I was.

These days, my best medicine is to spend an afternoon with one of my beautiful grandchildren whose kisses and cuddles ease away anything that ails me.

I spend a great deal of my time, in a voluntary capacity, as the consumer representative of the ACSC, and as a patient advocate and a volunteer for the Cancer Council's peer support Cancer Connect program.

In order to put a face to cancer survivorship, I tell my story often as a tool to inform, to educate and give hope. Doctors, nurses, technicians, students and others now have a fuller understanding of what life is like post diagnosis and treatment.





I am conscious of the giant capital C that is seared into one's forehead as soon as the words "I'm afraid you have cancer" are uttered. From that moment you are no longer Meg or Steve or Joan. You become a generic – you become "the cancer patient".

For everyone around you, it's as if the rest of your life fades into the background, all of its elements dwarfed by this massive thing that is happening to you.

And in many instances that is how we, the cancer patients, are viewed by those who deal with us professionally. Their focus is on treating and dealing with that oversized C, so perhaps sometimes it's easy to forget that we are whole, human beings with lives, families, jobs, interests, problems that now live concurrently with our cancer diagnosis.

During treatment and at its conclusion we have to deal with and return to these lives and their attendant complications.

**A simple "how are you today?" or "what else is happening in your life?" would often suffice.**

Attention is needed, a listening perspective adopted, to learn what are the stressors and complications of each patient's life and direct them to the supportive care that they need. To understand that there are barriers to treatment for many patients – amongst others, those of language, financial difficulties, work issues, complex terminology, distance from treatment, lack of a support network all complicating their cancer experience.

At Peter Mac, the term "survivor" is used to describe all cancer patients from the point of diagnosis. While not everyone diagnosed with cancer relates to the word "survivor" and each individual cancer journey and survivorship is unique, there are aspects we all share and which we recognise and acknowledge in others:

The hesitant yet triumphant walk to the front gate and later to the corner of the street. The meal no longer accompanied by the metallic taste of chemo. The milestone – the special birthday, being present to walk a child down the aisle or hold a brand-new grandchild. The moment of return – to school, to study, to work. The stumbling conversation with work colleagues and friends who don't quite have the words. The realisation that "new normal" has implications in all aspects of our lives – the way we look, the way our bodies function (or don't), the changes – both physical and psychological. The way our memory can be triggered by a sound, a smell, a scene in a movie or a play.

**Many of us are inspired by a need to give back, to help others in some way.**

We live very much in the moment, an accompanying whisper in the back of our minds before annual check-ups or the investigation of a new symptom. We are conscious of the concern of our family and friends – their fear around the "what ifs".

But for each of us, the thing that defines survivorship is the simple fact of waking up each morning to embark on the journey that is the new day.

It feels timely to re-tell my story at this time of the ACSC's 10th birthday celebrations, but also to undertake that retelling in a time of lockdown resulting from COVID-19.

Today our lives are circumspect and contained, our interactions conducted on screens; our healthcare professionals have become nimble and offer us, their patients, innovative solutions with telehealth, home treatment and shared care.

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I am reminded of the patience required, the slowdown imposed by treatments and their side effects, the remoteness of transplant, the isolation necessary when immune-compromised. The understanding that, for me, taking one test, one diagnosis at a time was what was required to compartmentalise the enormity of that thing called cancer.

**To read Meg's original story, along with a suite of cancer survivor stories, go to:**

[petermac.org/services/support-services/australian-cancer-survivorship-centre/survivors-and-carers/resources](http://petermac.org/services/support-services/australian-cancer-survivorship-centre/survivors-and-carers/resources)



## Resources

- **Australian Cancer Survivorship Centre:**  
[petermac.org/cancersurvivorship](http://petermac.org/cancersurvivorship)
- **Celebrating 10 years of ACSC:**  
[petermac.org/sites/default/files/media-uploads/ACSC\\_Highlights\\_2010-2020\\_1.pdf](http://petermac.org/sites/default/files/media-uploads/ACSC_Highlights_2010-2020_1.pdf)
- **Australian Cancer Survivorship Centre resources for survivors and carers:**  
[petermac.org/services/support-services/australian-cancer-survivorship-centre/survivors-and-carers/resources](http://petermac.org/services/support-services/australian-cancer-survivorship-centre/survivors-and-carers/resources)
- **Common Survivorship Issues Directory:**  
[petermac.org/survdirect](http://petermac.org/survdirect)
- **Cancer Council 13 11 20**  
[cancer.org.au](http://cancer.org.au)
- **Cancer Council "Living well after cancer":**  
[petermac.org/sites/default/files/Living-Well-After-Cancer.pdf](http://petermac.org/sites/default/files/Living-Well-After-Cancer.pdf)



**Australian Cancer Survivorship Centre**

Celebrating *10 years* of progress

**Australian Cancer Survivorship Centre**

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