

## **“SURVIVING IS NOT ENOUGH”**

### **ASHLEIGH MOORE INAUGURAL ORATION**

**2015 FCIC Survivorship Conference, 6-7 Feb 2015, Adelaide SA**

(Flinders Centre for Innovation in Cancer)

*Sally Crossing AM*

The Oration was established to recognise the significant contribution of Ashleigh Moore to the field of cancer survivorship in South Australia and beyond.

To commemorate Ashleigh’s lasting contribution to the care of those affected by cancer, the Flinders Centre for Innovation in Cancer established the annual Ashleigh Moore Oration to recognise an individual or organisation in Australia who has made an outstanding contribution to the care of cancer survivors through contribution to clinical practice, research, policy, and/or advocacy affecting cancer survivors.

The inaugural Award was presented to Sally Crossing AM who gave the Ashleigh Moore Oration to the 2015 Survivorship Conference. Her text follows.

Good morning & thankyou for the warm welcome.

Such an honour to have been chosen to give the inaugural Ashleigh Moore Oration.

I am especially pleased, not only as I know a number of fine potential “inaugurators” were considered, but because choosing a cancer consumer advocate to give this first Oration is absolutely appropriate. And Ashleigh would have been mightily pleased.

Apart from my own 18 years in this important new business of **making sure that the voice of people affected by cancer is heard wherever decisions with impact for us are made**, I have another claim to be scene setting: I too am a true blue survivor, having notched up 20 years exactly and still going fairly strong.

I am really thrilled that this two day conference, on the extremely important topic of survivorship, has been developed and finessed WITH informed cancer consumers, and these sourced largely and appropriately from our sister consumer organisation Cancer Voices SA. WITH is in capitals because it is very different to FOR – which was so often the case (even with the best of medical model intentions). The conference content team were right on the ball in recognising from the start that WITH consumers is much more productive for everyone, than FOR them. You may hear this as a bit of chorus throughout my address.

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#### **Ashleigh Moore and me**

As survivors of our cancers, Ashleigh and I became very close partners in cancer consumer advocacy – working hard as volunteer advocates to improve the experience for others like ourselves who had inadvertently joined the Big C Club. No mean challenge – especially now that cancer kills many more Australians than any other cause of death, as well as being the greatest disease related burden for our society. Around 130,000 Australians will be diagnosed this year – reaching 150,000 in 2020. Not only do we die of our disease, but many more of us are living with it and “surviving” for much longer than before. I am a case in point and so was Ashleigh until this time last year. Survivorship, however we define it, has become a priority.

Ashleigh and I met though our shared enthusiasm for an **independent cancer consumer “voice”**. Cancer Voices, my home cancer consumer advocacy organisation, and his, began in 2000, initially in NSW. The concept soon spread - sometimes with the help of state Cancer Councils responding to our prompting and their own recognition of its value.

Ashleigh and I introduced ourselves at a COSA conference in Melbourne in 2006.

We were both there to update ourselves on cancer research, to network and to represent our own state Cancer Voices groups at an annual Cancer Voices Australia meeting. We hit it off, bounced ideas between each other and began a partnership which leveraged our different cancer and life experiences. I think he did a bit more talking than I was able to. We also became good friends, as you often do in this club. We even lived together for four winter weeks at my place in Sydney when Ashleigh underwent some fine-tuned radiotherapy at my local hospital, Royal North Shore. It was during this time that my husband and I discovered that Ashleigh was an excellent subcontinental cook. Those freshly made curries and great dinner conversations about how to fix everything to do with cancer, remain highly memorable.

The personal relationship developed into something bigger. Cancer Voices NSW and Cancer Voices SA have been great collaborators ever since. I acknowledge Julie Marker's fantastic stewardship here in SA over the last couple of years. But, one thing we in NSW never got to grips with was eye-catching group cycling, despite a short lived and wobbly attempt to emulate our yellow and black two wheeled SA cousins.

**I hope most of you had the pleasure of meeting Ashleigh Moore** – a great Australian, a great cancer consumer advocate and certainly no shrinking violet. His own cancer and survivorship experiences seeded a passion to make the proverbial difference. His own survivorship was definitely “not enough”. Ashleigh's contribution to making sure that the voice of independent, informed consumers was a real part of decision-making about cancer policy, services, research and care was huge, not only in his home state, but nationally AND internationally.

At the launch of Cancer Voices SA, Ashleigh said: “health services and associated organisations must shift their thinking to “really “listen to consumers and their invaluable “lived experiences” – the experience that not everyone can imagine or even know until they have walked in our shoes” (Launch of CVSA Nov 2007). People like Ashleigh Moor are role models who forge the way in our movement, showing us that we should never be afraid to “raise the voice”.

The slightly provocative title of my talk is “**Survivorship is not enough**”. I choose this to consider two questions: firstly, while the term resonates happily with many, it seems open to the interpretation of whoever is using it. I suggest we could come up with a clearer definition. And I'll float some ideas from both my own viewpoint and from that of the collective – the view of the many, which most of us see as the most valuable.

Secondly, for many of us survival is just not enough – once over, or between, the rigours of cancer treatment, we tend to reflect about and want a richer, fuller life ourselves and for others. Going back to “before” cancer for many is hard and often unwanted. We have changed. The change which Ashleigh and I experienced, as thankfully have many other cancer consumer advocates, led us to using our life skills, pre cancer careers and own cancer experiences toward making a really big difference. Persistence, commitment, optimism and a degree of fearlessness helps too.

Practically, now, I would like to see this second conference come up with solid recommendations about survivorship, which we can take away and implement. They might be in the form of some kind of Guidelines which tell both practitioners and their patients what they should expect. I am very keen on Guidelines, not only having been a policy wonk in my pre cancer consumer career, but because we find them so useful during our cancer “journeys”. They help us to understand options, reasons for them and what to expect – very reassuring as we navigate that crooked pathway. I swing about a bit re rigid evidence bases. Sometimes the words of the then CEO of the World Cancer Research come to mind – “was there ever a clinical trial to prove the efficacy of using a parachute to jump from a plane?” I heard him tell that one at a big cancer conference and suggest it can apply to many of the debated aspects of survivorship. And a parachute would be good too - or am I mixing metaphors here?

### **What is survivorship?**

Is it a skill we patients should learn, or is it a bigger term describing how we handle our cancer from go to woe? Obviously we need to decide just what survivorship is.

We consumers see it as beginning at our first diagnosis, and extending right through the cancer journey. Many of the neat diagrammatic descriptions get it right until they assume treatment has “ended” at some point. In real life, cancer treatment can never be thought to have ended until death. Cancer has a nasty habit of sneaking back. Just as early diagnosis of the initial disease is a driver for better outcomes, so is early catching of recurrence and progression. And because we have so little hard data about recurrence and metastases, prediction about time to treatment “end” is not possible. Our health authorities trumpet the improving five year survival rates; some even, nicely for us, estimate the ten year ones. Most of us survivors are rather more interested in a lot longer than that – and the fact that there are so many more of us living with our cancer rather than dying quite quickly, means ...guess what – we now have an awful lot more survivors to help. The figure is about 900,000 over the last 28 years (AIHW). And we know that if we do look after them, their survival in all aspects is greater. I understand that evidence for this does indeed exist, as well as its being common sense.

### **Care coordination**

Another major point I’d like to put up front is **cancer care coordination** and cancer care coordinators – and in both public and private settings (cancer is increasingly being treated in the private sector as we know). There have been conferences and evaluations on this topic; some states fund positions, and some charities do the same, eg those for breast and prostate cancers. Some studies have even shown that care coordination is seriously cost effective. But there remains confusion – what is their role, who should actually do it, what happens once hospital based treatment is over .... Again I’d like to see best practice guidelines (or similar) developed to clarify expectations and what ought to be provided. Cancer care coordination is an important aspect of survivorship.

### **Cancer Care Plans are an integral part of survivorship**

We cancer patients want these badly and for obvious reasons – no clinical trials needed here either, it’s simply good planning and management. Treatment and care plans give cancer patients and their families huge reassurance about how to successfully navigate and make major choices – often the most frightening thing in the cancer experience.

### **Models for survivorship – what works?**

I was lucky to hear and to meet Mary McCabe, of Memorial Sloan Kettering Cancer Centre, at the recent COSA conference. Her presentation, which she has willingly shared, offers a good overview of what really matters in survivorship, including guidelines for follow up care and care plans.

Of course, there are different models, with their different pros and cons. The need and the basic concepts are clear - but deciding what will work best and in what setting is something else. Here are the eight main components, with a little help from Professor McCabe, of well supported survivorship from my perspective - not simply as an individual, but as a cancer consumer advocate with strong linkages to the brother and sisterhoods.

- surveillance for recurrence of the primary cancer and metastases
- monitoring and managing late treatment and psychosocial late effects
- providing follow-up recommendations for detection of second cancers
- information about survivorship issues and how to find community resources
- healthy lifestyle information
- reviews of treatment summary and care plan
- communication with GPs and “shared care”
- empowering survivors to self-manage and advocate for their own health needs

### **And now, my story – how getting cancer leads to wanting to make that difference**

Some of this is ancient history, as I have managed to survive breast cancer – and cancer consumer advocacy - for quite a long time, 20 years in fact. I was just 49 when I self-detected a lump in my left breast. This was followed by not very satisfactory surgery and perfectly fine radiotherapy, the accepted treatment for early breast cancer in 1995. No chemo or Tamoxifen recommended in those days.

After publishing some reflections on those early experiences, I was invited by the then National Breast Cancer Centre to do a short training course in consumer advocacy and research. That switched on the proverbial light, and I could see how, using my existing paid-career skills, I could do some meaningful giving back (not something which had interested me until then) and make a real difference for other people. I soon left that paid career and formed the Breast Cancer Action Group NSW in 1997. We then broadened our reach, and increased the volume of the “voices” by setting up Cancer Voices NSW in 2000. Cancer Voices Australia, with which I remain very involved for national level issues, followed. I have most recently set up the Australian Cancer Consumer Network which links 30 cancer consumer groups – some generic like Cancer Voices and other for specific cancers. This was launched in federal Parliament November by the Parliamentarians Supporting Cancer Causes. From little things (read IDEAS), big things grow!

My own cancer keeps returning every few years to remind me what that “journey” is really like – biopsies, lumpectomies, radiotherapy, one mastectomy, a liver resection, CT scans, MRIs, PET scans, endocrine therapies, an MTOR inhibitor, – don’t ask... and probably the dreaded chemo soon. But so far, although metastatic for many years, we (my medical team and I) are keeping it fairly well at bay. Luckily there are now drugs which were only a twinkle in the eyes of researchers when I was first diagnosed which are more targeted for my kind of breast cancer. The two I now take are subsidised via the Pharmaceutical Benefits Scheme – so thanks go to the compassionate taxpayer. Yet there is no certainty that these will work, a fact that all cancer patients ultimately have to live with. My story is an example of the changing nature of the cancer experience, a change which will mean many more of us will be round a lot longer, all very keen on surviving as well and as long as we can!

### **Some reflections**

If I hadn’t developed and lived with, and so far survived, cancer I certainly would not have had this extraordinarily rewarding career of cancer consumer advocacy. Ashleigh Moore would have agreed strongly that committed individuals who come **together** with determination and passion can and do move quite a few mountains. Just give us time, and help us survive please!

My message here is that the collective of willing, informed, inspired and networked individuals is the strength of the “voice”. Individuals alone may help but do not have the credibility or the power of the many. This is a basic democratic concept, nothing new at all. And we know it works.

**I should give you a bit of historical context:** Last year we celebrated the twentieth anniversary of the Australian cancer consumer movement.

It began in Melbourne in 1994 by a group of women with breast cancer (yes, we have indeed led the field and are have always been keen to share what we’ve learned) who developed a vision for getting consumer input into decision-making about treatment, care even the direction of research. It was initiated by the experience of one passionate woman, but she was smart enough to understand the much greater power of many voices calling for the same thing. Their first advocacy action was to successfully get the drug Taxol onto the PBS. More about this in the brief history of the movement and its significance which I wrote for the November issue of the journal *Cancer Forum*.

## What have we achieved?

Exercising the louder, persistent, independent and informed voice has brought all sorts of improvements to the cancer journey. These are recorded in publications, newsletters and on the websites of consumer groups like Cancer Voices. For example, more comprehensive cancer centres, better access to cancer drugs and radiotherapy, research which reflects consumer priorities, formal training for consumer reps, better information, more guidelines and with consumer input, directories of cancer specialists, a website to find suitable clinical trials, programs for nominating informed consumers to work with researchers and policy makers, service and support providers, more palliative care services, even legislative changes. Many achieved, some ongoing, always more decisions to be influenced. Including the survivorship agenda!

## Recognition

I am proud to have been in the thick of it for many years and of proud of recognition by my country through being awarded Member of the Order of Australia in 2005 for cancer consumer advocacy. Even prouder perhaps to be recognised by my old alma mater, the University of Sydney, which gave me an Honorary Doctorate last year. The citation was for *“for extraordinary leadership and contributions to supporting those with cancer from diagnosis, through treatment, care support and survivorship, in both advocacy and research”*. This was not only a wonderful thing for me, but even more so for the movement’s mutual cause – on my own it would have been impossible to achieve what we have.

So dear audience, when you find yourself wanting to engage with informed survivors who can offer the broad and independent view, turn to a health consumer organisation – like Cancer Voices in the cancer field. Our nominees have experienced the cancer journey and have had training to understand how to provide the broad view of the many, not just their own.

The familiar catchcry of **Nothing about us without us** sums it up very well.

There are many ways in which survivors, especially networked ones, can use their unique skills, knowledge, work and life experiences and there is no shortage of things that need fixing! The value of consumer input into this conference alone, in planning, presentations and discussion, will be obvious during our two days together. We survivors can invaluablely inform your policy, research and services. And this applies to the field of survivorship itself as much as to anything else – if not more! We look forward to continuing to work with you very closely....

THANKYOU

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Cancer Voices Australia is the independent, 100% volunteer voice of people affected by cancer, working to improve the cancer experience for Australians, their families and friends. We are active in the areas around diagnosis, information, treatment, research, support, care, survivorship and policy.

To achieve this we work with decision-makers, ensuring the patient perspective is heard.

Cancer Voices has led the cancer consumer movement in Australia since 2000. Its networks work together on national issues identified as important, with consumers working to help others affected by cancer.

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