

## Ashleigh Moore OAM – a Cancer Voices SA tribute

Because of cancer, Ashleigh is not here. Because of cancer, so many of us **ARE** here in this Chapel today – here because of what Ashleigh has done on behalf of people affected by cancer.

As a close colleague & friend I'll describe the extraordinary Cancer Voices chapter of the past 7+yrs of Ashleigh's life.

Against the odds, Ashleigh survived advanced head and neck cancer in 2005. That was a feat in itself, surviving the treatment as aggressive as the cancer, the disfiguring surgery, debilitating

chemotherapy/radiation treatment regime.

Even things we take for granted like eating, swallowing– these were all things he took years to recover from, along with the nightmares and withered arm and shoulder rehabilitation.



To recover was remarkable, but what Ashleigh chose to make from this harrowing experience is what sets him apart.

Many people get cancer, but Ashleigh 'raised a voice for people affected by cancer' in a way that **IS** truly extraordinary.

Ashleigh, using his unique skills and engaging, courageous, tenacious temperament spent the last 7 years as a volunteer blazing a trail unlike anything seen before in cancer advocacy at the local, national and right through to international level.

During 2005 Ashleigh found the online cancer support of the LIVESTRONG Foundation, their practical resources, resonated powerfully with him by coming **from** cancer survivors **for** survivors. These guys really understood what was he needed!... along with the empowering motto: Unity is strength, 'Knowledge is power, Attitude is everything'. Unity was the strength of his family unit with Justine and 2yr old Brook to support him. His wife Justine was the 'detective', searching out the Knowledge and information to advocate for Ashleigh's care that proved vital, absolutely vital, to navigate him through the complex health system. Attitude was the HOPE and determination allowing him to pull through, get back on his bike to exercise and rehabilitate his ravaged mind and body. Cancer was a life-changing experience, he got a 'cancer survivor' qualification and a whole new perspective.

Ashleigh was fortunate in being able to retire from his stressful career, and after recovering, could have put his feet up and done many things for purely personal pleasure.

But no, in late 2006 Ashleigh turned adversity into a new mission by establishing the health advocacy movement Cancer Voices South Australia.

Though he greatly admired the example set by LIVESTRONG and this guided him, Ashleigh's innovation, leadership capability, tireless energy **and** his ability to 'talk the leg off a chair' forged something with his own flavour. Cancer Voices NSW and its founder Sally Crossing was also a guide and mentor.

With his 'Safety & Quality' background he recognised that 'good systems and not relying on good luck' was something surprisingly lacking in our health system, and patients needed their voice and the patients' perspective to be heard.

His '**obligation of the cured**' was to use his experience to help smooth the path for others, to speak up, speak out and work effectively to demand change. To rail against inequity and injustice, so 'worlds best cancer treatment and care' wasn't only available if you were white, well-off, well educated or had particular types of cancer. Access to services people need, not just what the health system wants to offer.

Ashleigh didn't see barriers, he just went right through them. He wasn't afraid to take things to the highest level. He knew the power of even one voice in creating change, but drew strength from knowing his voice was representing the collective voice of hundreds.

In something akin to 'baptism by fire', in its first year Cancer Voices SA became a force to be respected and reckoned with. This was through Ashleigh's exemplary campaigning around a radiotherapy issue affecting almost 900 cancer patients – which Ashleigh ironically discovered later, included himself. Changes following from that action have 'made a difference' to this day.

That radiotherapy campaign was such a personally acrimonious and bruising time that we just wanted some 'respite'. Ashleigh heard that Lance was returning to cycling, coming to Adelaide for the Tour Down Under (TDU) and launching a new Global Cancer Campaign. This news prompted Ashleigh to suggest forming a Cancer Voices SA cycling team to ride in the 2009 TDU Community Challenge Ride. He only needed 5 riders to form a team, yet Ashleigh recruited 123 – and set a new record for a community team in the history of the Tour!

That was Ashleigh, always setting a new record or raising the bar that bit higher.

Ashleigh's engaging personality and thoughtful words seen on TV and in newspapers made people want to get involved and Cancer Voices grew exponentially from 50 to over 800 members in a short time...& not all cyclists.

2009 was an incredible year. Ashleigh started using Twitter – which led to an interview with LIVESTRONG CEO Doug Ulman, which commenced an association that lasts to this day..

Only Ashleigh could make things like this happen!

People met Ashleigh and he left a big impression.

Ashleigh's connections went from local & national to international !

Ashleigh was invited to speak at the LIVESTRONG Global Cancer Summit in Ireland in 2009, 1 of 7 advocates, in a presentation live-streamed to millions around the world . On this international stage he vowed "*Cancer almost robbed me of the chance to be a father, husband and respected son*". "*I want the next generation to never have to face the brutality, fear and uncertainty I suffered through the course of my cancer treatment. I want to make a difference*".

Quite extraordinary how through being a cancer survivor, sharing his wise observations and lived experience, all of this was unfolding and good things were achieved. He started to break the stigma and silence to change attitudes about cancer. His example helped "patient advocates" become respected *as a group* for the value gained from hearing our experiences.

However, trouble seemed to find Ashleigh, or he finds trouble, and in Sep 2010 a new cancer roller-coaster commenced. Ashleigh was diagnosed with lung cancer – unbelievably after a 'flaw in the system' led to discovery of his diagnosis being delayed for months after the scans. Numerous other 'incidents' continued to happen which drove Ashleigh to continue advocating. If things like this

happen to a well-known, vigilant, intelligent, system-savvy person like Ashleigh, what happens to the average person!

He was in for the 2<sup>nd</sup> 'fight of his life'. More surgery, and months of chemo and radiotherapy. This time Ashleigh did his own research using his networks now formed round the world to help him. Justine was busy looking after their 2 beautiful daughters, Brook and 2yr old Erin.

Despite having only one lung, Ashleigh continued to ride with the cycling group every Sunday morning, inspiring and amazing everyone. He often said that he used to lead from the front of the pack, and now he led from the back.

And he didn't save his breath – he would talk all the way up the Hills to anyone who would listen!

The pleasures from cycling team friendships made the advocacy work sustainable.

This courage caught the attention of Lance Armstrong. Ashleigh finally managed to meet Lance . Ashleigh organised a ride down to Glenelg, inviting about 100 Cancer Voices cyclists all wearing the distinctive jersey designed with flair and meticulous attention-to-detail by Ashleigh and designer Jo West. (He's wearing this jersey now, so he's ready to go riding those cloud bikes.)

For three and a half of the past 7 years Ashleigh battled lung cancer. As a non-smoker, he railed against the stigma of lung cancer, and inequity in funding and research for lung cancer. ... . His advocacy has been as varied as it has been constructive .

Always at the leading edge of innovation, Ashleigh led the way using FaceBook for continual engagement with his mix of personal, funny or thought provoking observations...and photos.

Ashleigh's achievements in cancer advocacy were rewarded by an Order of Australia Medal announced on Australia Day 2012, for exceptional service to the community through Cancer Voices SA. This later led to Ashleigh meeting Prince Charles through an invitation from the SA Governor the Honourable Kevin Scarce. Against the odds - Ashleigh positioned himself to ensure a handshake with Charles, and in true Ashleigh form, shook his hand and would not let go till he had told Charles all he wanted to say about Cancer Voices, and was certain a good photo or two had been captured to post on FaceBook.

It hasn't all been fun and bike riding, and there has been a huge amount of hard-yards, long hours, incredible pressure, sacrifice and personal acrimony for speaking up. But they don't come any tougher than Ashleigh, unwavering in his resolve when he set his mind to it!

You might have thought having lung cancer come back in mid 2012, that he might have slowed down to re-examine his commitment to heading up Cancer Voices and the elite LIVESTRONG leader group. But no .. as a THREE TIMES cancer survivor he forged on with rebuilding Cancer Voices Australia, public speaking , other projects .... including a cheeky plans to get the perfect battery-power-assisted bike so he could race us up the Hills, leading from the front once more. Unfortunately this never happened as his time ran out.

Cancer came back for a fourth time with a vengeance in June 2013. He never gave up, forced himself to travel interstate for clinical trial treatments and pushed himself to continue to exercise.

His greatest regret was being too ill to ride his beautiful new bike.

There are so many connections all around the world, people who have come to know Ashleigh through being a Livestrong Leader, his TV, newspaper, online social media and other cancer advocacy efforts . He helped countless others go through their cancer journey, yet so often this was while Ashleigh was going through cancer treatment himself, and his own health and future was uncertain.

Ashleigh was incredibly proud of a 'Certificate of Outstanding Leadership that he received from LIVESTRONG very recently. He truly was inspirational.

He was also unstoppable. Even in the last 6 months of his life when he couldn't physically 'raise a voice', he could only speak in a whisper, he was still at it, telling the Hospice nurses about Cancer Voices activities, advocating for the treatment and care he wanted.

In addition to all the 'amazing' things that Ashleigh did, part of his genius was the way he inspired others to believe in themselves, that they too could make a difference, and achieve things we wouldn't have thought we could.

He certainly showed us all how to be exhaustively proactive in researching your care options, and how to fight, fight and fight against cancer. It seemed he survived on sheer willpower, that incredible 'will to live' for his beautiful family.

He defied 'cancer gravity' so many times – we almost came to believe he might be invincible. Sadly this wasn't to be.

In 56 years Ashleigh packed in a full and remarkable list of achievements.

Cancer Voices was a significant part of these past 7 years, and for that we must also say 'Thank You' to his family Justine, Brook and Erin, because they have been so extraordinarily generous in sharing, sacrificing and tolerating all the time and cost supporting Ashleigh's work as a volunteer and advocate. Be incredibly proud for your part in this.

With ingenuity, style, wit, intelligence, warmth, integrity, clarity, tenacity, determination, persistence, strength ..... the legacy from Ashleigh's Cancer Voices work is formidable and will continue to 'make a difference' for a long time ahead.

Many people get cancer, but few have 'raised a voice and made a difference to the lives of others' so effectively as Ashleigh.

We have been privileged to have known you.

You are a hero to so many, a legend!

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Julie Marker, On behalf of Cancer Voices SA Executive Team, 11 February 2014

Cancer Voices SA

Raising a voice for people affected by cancer.

[www.cancervoicessa.org.au](http://www.cancervoicessa.org.au)

Rest in peace Ashleigh Moore OAM (1958-2014) - such a pioneer for cancer advocacy at the state, national and international level. He made a huge contribution. His volunteer efforts have helped improve the experiences for countless others as they go through their own cancer journey, even while he was going through his. He will be deeply missed.