

## Love Your Sister's Connie Johnson determined to keep making a difference as she faces death

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Connie Johnson is dying but she hasn't given up on life.

The Canberra mother-of-two, who has terminal breast cancer, could have happily retreated from public life after her brother, the actor Samuel Johnson, raised \$2 million for breast cancer research when he rode a unicycle around Australia in 2013-14.

But now, their fundraising campaign, Love Your Sister has reset the target to \$10 million for breast cancer research including raising \$1 million in one day next month through Love Your Sister's almost 280,000 Facebook followers.

The Power of Three day will ask each of the followers to donate at least \$3 – hopefully more – and raise potentially \$1 million in one July day for the Garvan Institute of Medical Research.

"Can we get people to take the next step? People can like us on Facebook but collectively can we show we want a cancer-free future or at least a future where cancer no longer kills?" Connie said, in the warm lounge room of the family's Kingston apartment.

"It's going to be a little experiment. If it takes off, we will do it every year."

July 26 also marks five years since Connie was diagnosed with terminal breast cancer and told she may have six to 12 months to live.

More importantly, it is also her older son Willoughby's ninth birthday. Younger son Hamilton is eight in September.

"They were three and four when I was diagnosed and Sam and I were three and four when our mum died and we have no memories of our mum." she said.

"That was very hard thinking my children wouldn't remember me. Now I know they are old enough to have a memory of me, it might be weird little memories of me but at least they will have them for the rest of their lives."

A still, calm presence, Connie is now receiving palliative care, including palliative radiation to help relieve the pain caused by tumours in her spine.

The pain has subdued but she was made incredibly sick by the radiation.

The cancer has now spread throughout her body.

It is heartbreaking to hear her talk about Hamilton climbing into bed with her because he has nightmares about "Cyclops and Sandman and cancer".

"For my illness to be lumped in with super villains is really sad," she said, adding she and husband Mike have had to change the conversation around cancer with their children as they have gotten older.

"It used to be, 'Mum is doing all she can, she is taking her medication and seeing the doctors to make sure she gets better and now it's, 'well, are you going to get better at all?' I don't want to lie to them but I don't want to scare them either. If I lie to them how will they trust me on anything else? We talk to them in a way they can swallow. My doctor said I might live another one or two years. I don't want to lie to them. It's a tricky balance."

There is definitely plenty of goodwill for Connie and Love Your Sister, a campaign that was only meant to last as long as Samuel's unicycle ride but which has taken on a life of its own, continuing to raise money for breast cancer research and awareness, including through the sale of merchandise and jewellery.

Social media has been key to its success.

"It's not uncommon to get 30,000, 40,000, 50,000 likes on a post and literally thousands of comments, especially anything to do with my health and how I'm going," she said.

"It's mainly other mums who are followers and I guess what happened to me, could happen to any of our followers and it has.

"A lot of people have been checked and diagnosed because of that early detection message.

"Sam wanted to know what my legacy would be and I wanted to save at least one other mum from having to say goodbye to their kids and I believe that has happened."

A former disability support worker and manager, Connie's position with Love Your Sister is unpaid but gives her "a lot of pleasure and a sense of purpose".

All the money has gone to the Garvan Institute, save for \$200,000 that went to The Cancer Support Group (formerly The Eden Monaro Cancer Support Group).

The institute also recently announced that breast cancer researcher Dr Elgene Lim had received the inaugural Connie Johnson Fellowship in Breast Cancer, allowing him the freedom to do his work without having to also apply for funds.

Connie's own diagnosis came late into the disease and early detection remains her main message.

"I saw doctors for about a year trying to get diagnosed and had I put my foot down and asked for a scan I would maybe not be dying now and all my treatment would be over and I'd be back at work and trying to pay off my mortgage like everyone else," she said.

She is also planning another big project in 2016 – The Bucket List Initiative which will urge people to tick off something they've always wanted to do, big or small, and raise money for cancer research through Love Your Sister.

"Since I've been diagnosed, people say to me, 'Oh, if I was dying I'd go overseas'. 'I'd just eat chocolate'. 'I'd quit my job and spend more time with my family'," she said.

"They tell me what their dreams are if they were dying, almost as if dying would give them the freedom to make their dreams come true."

Connie candidly says "dying is a full-time job for me" – there is the medication, the treatments, the doctor's appointments, the need to sleep up to 16 hours a day.

She wants people to embrace the now – don't wait until you're dying.

"So we're urging people to do the things they want to do 'one day'. 'One day when the kids grow up'. 'One day' when they retire. 'One day' when they get enough money. Why not make one day, today?"

"It could be just planting a rose bush or going to see their grandmother. It doesn't have to be large or extravagant.

"In a way we're all terminal and we're all going to die. We have the now and we have to do something with it."

There is little doubt Love Your Sister works to make a difference, and will continue to do so.

Connie says women are heeding its message.

Even Samuel, who had to endure the suicides of his mother and later his former girlfriend, has been changed by the whole experience, says Connie.

"He's found his happy. He's just back to the Samuel I knew as a kid before life happened. He's enthusiastic and happy and positive. It's a beautiful thing to see."

As researchers work on breakthroughs such as genetic work that can more easily match the correct drugs with the right cancer, Connie is excited that Love Your Sister is contributing to fighting breast cancer, a disease which one in eight women will develop in their lifetime.

"That makes me feel nice," she said.

"Someone in the future won't even know what Sam and I did but they'll be able to go back to their family after treatment and go back to living a normal life and won't even know it came from this and that's beautiful."

*This story was found at: <http://www.canberratimes.com.au/act-news/canberra-life/love-your-sisters-connie-johnson-determined-to-keep-making-a-difference-as-she-faces-death-20150606-ghhk65.html>*