

## Love Your Sister's Connie Johnson speaks about life, love and death from her Canberra hospice bed

Connie Johnson says she is determined to stay alive for her younger son's 10th birthday in late September as she walks "a knife-edge" between life and death in a Canberra hospice.

The face of Love Your Sister could at any point succumb to liver failure but this week when talking to Fairfax Media clarified she was stable and had found peace at the hospice Clare Holland House but still had hopes to be able to die at her Canberra family home.



Connie Johnson spends a lot of her time in Clare Holland House colouring in; her original designs planned to be made into greeting cards and prints to raise money for Love Your Sister. *Photo: Sithixay Ditthavong*

"I'm still here. I'm feeling more positive. I feel like I'm getting the comfort that I came here to get, psychologically. And the space and the treatment I've received, getting all my drugs right, I'm starting to feel like me again," she said.

"The messages of love are coming through loud and clear.

"It's a really hard time in our lives. It's really hard to me, for [husband] Mike, for [sons] Willoughby and Hamilton and for [brother] Sam. But there is still a lot of beauty. A lot of love. Hope. Empathy. Unity."

Ever since she was [admitted to the hospice in early July](#), there has been public speculation about the fragility of her health and her prognosis battling terminal breast cancer.

Connie, 40, wanted to speak out, clarifying her health status, which has shifted from initially dire when she entered the hospice to now more stable.

And she has talked candidly about the fact she has found it difficult to transition away from the work of Love Your Sister, which had consumed her for five years, raising more than \$5.6 million and awareness for cancer research.



Connie Johnson outside Clare Holland House in Canberra on Monday. Her jumper reads: "Let Me Dream Longer". "I like that," she says. *Photo: Sithixay Ditthavong*

"I've been told I really suck at retirement," she said, with her beautiful smile still in place.

And, heartbreakingly, she has addressed the realities of having to move from preventative to palliative treatment for breast cancer that has attacked her liver. To admit the end is near and the impact that has for her two boys, Willoughby, who has just turned 11, and Hamilton, who turns 10 on September 26.



Her health has declined but Connie Johnson's iron will is evident in her beautiful colouring in - staying inside those lines no matter what. *Photo: Sithixay Ditthavong*

"The conversation has had to change from, 'We're still working, there's still options' to 'There's no options left and we have to come to terms with the fact mummy's going to die'.

"So the natural question any child asks is, 'When?' and we can't give them that answer," she said.

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Connie Johnston on explaining her health status to her two sons.

"I would be very surprised if I was still around at Christmas. I'm just hoping against hope that I'm still around for Hammie's birthday on September 26."

Connie has also wanted to talk about the enduring impact of that magical day in May when [Love Your Sister's Big Heart Project raised more than \\$2.2 million for cancer research through five cent pieces](#) being tossed on to netball courts in Lyneham. The project was Connie's dream.



Connie Johnson with husband Mike and sons Willoughby, now 11, and Hamilton, who turns 10 in September. *Photo: Facebook/Love Your Sister*

"The memories from the Big Heart Project sustain me every day," she said.

"It's mindblowing to know that our community is so strong and I'm part of it. I'm so proud to be a Canberran, alongside every Canberran who reads this article. It's real, it's real."



Connie Johnson luxuriating in that sea of 5c coins, worth more than \$2 million. She says the Big Heart Project "sustains her every day" she is in the hospice, with memories of the

strength of her community. "I'm so proud to be a Canberran," she said. *Photo: Facebook/Love Your Sister*

Since the Big Heart Project, Connie's health has declined. She is no longer able to use a walker but is restricted to a wheelchair; her torso is distended as her liver has tripled in size, making it difficult to bend over or sit on a chair. Her stomach has shrunk to the extent if she eats even a little too much, she vomits spontaneously. She is connected to constant morphine relief.

Her husband Mike and her children have been her focus. Willoughby likes to sleep over with his mum; Hamilton needs to just check in to see she is OK.



Love Your Sister's Connie Johnson enjoying the early spring blossom outside Clare Holland House on Monday. *Photo: Sithixay Ditthavong*

"Over time we talked to the children and as they've gotten older, we've had to change the narrative from, 'We're doing the best we can to find medicines that will make mummy live longer' to 'There are no medicines left'," she said.

"One child [Willoughby] has had the the approach, of, "OK, let's do more fundraising. Get back to work. You can't retire, Mum, you're too good at this, you need to keep going'.

"He has basically asked me not to retire and the other day presented me with a business plan for all the ways we could raise money for Love Your Sister, like Love Your Sister trading cards and all sorts of things.

"And he's very much focused on that side of things, where he feels he is doing things he can help, whereas Hammie has gone into himself a bit. It's very difficult for both of them to cope."

In her room in Clare Holland House at the north-eastern edge of Lake Burley Griffin, Connie can look out the sliding door to people jogging and cycling past, along the Molonglo River. The room has family photographs, balloons are arranged in one corner, a colourful quilt covers her bed.

She spends her days making friendship bracelets and colouring in. Her exquisite original designs are planned to be turned into greeting cards and prints to fundraise for Love Your Sister.

She can still delight in the little things. "Oh, that's lovely, thank you," she says, as she sips a peppermint tea someone makes for her. She revels in the beauty of a parrot nibbling the grass under early-spring blossom outside the hospice.

"I didn't think I'd see spring. And look - it's spring," she said.

Connie revealed to *The Canberra Times* in April [that she had decided to cease all treatment](#) for the breast cancer she had been battling for seven years, no longer prepared to accept the toll on her body as the cancer attacked her liver.

She says now she was naive about accepting that was the end and did try chemotherapy again, with terrible side effects, losing 10 kilograms. She was offered hormone treatment but decided no more.

Her decision to go into Clare Holland House came as her cancer "markers" continued to rise and rise. For most of her cancer treatment over nearly seven years, they had been at 15. By the time she decided to go to the hospice they were in the 2000s. Her pain management at home was not working. She was suffering stress, infection and even a medically-induced delirium, including psychosis.

"We were talking days or weeks of survival at that point," she said.

"The liver had expanded so much; the cancer had grown so much and there was only a very little part of the liver still working. You only need a small amount of your liver to survive. Hence, why someone with alcohol abuse problems can live for 20 years with a shot liver.

"But because of the acceleration, we thought that that last little bit of healthy liver would be taken over very quickly. That hasn't been the case.

"I had the choice to go into the hospital and have the liver actively treated, but there's not much they can do. And then I ended up coming here because I was more comfortable here, than at the hospital.

"It's been really good for the management of my drugs, getting everything balanced and right."

Connie candidly reveals she was also suffering from the stress of leaving behind Love Your Sister, the organisation she and brother Samuel had seen grow and grow over five years, raising millions for the Garvan Institute of Medical Research.

She said retiring from her work to focus fully on her family wasn't a smooth transition. She felt she was interfering in her boys' routines. She didn't want to impact on the authority of her husband Mike who had been their children's primary care giver for five years.

She went home after the Big Heart Project and crashed and burned.

"It sounds like you go, 'Oh, yeah, that's over, let's go to the zoo. Let's go and do all these things'. It just wasn't that simple," she said.

Before going into the hospice, the psychosis meant she was hearing and seeing things that weren't there and speaking to people who weren't there. It continued in Clare Holland House for about 10 days.

"I came here to be more comfortable and die more peacefully than I was at that point," she said.

What happens next is still uncertain.

"If that little bit of healthy liver I've got left gets taken over by the cancer, then I go from walking this fine line which is high-level liver dysfunction, into liver failure. And once you go into liver failure, you've got a week or two and you're gone.

"So my life expectancy right now, even though you're sitting here with me and I appear quite strong and well, I could go into liver failure overnight and I'll have a week or two.

"It will be me sleeping, lots of drugs, bunker down, family-only time. It could happen that the healthy part of the liver is maintained for a bit longer. If I go home in this sort of state, it would be with the hope I get a month or so more, walking that knife's edge, before I die.

"Or if I stay here, I stay here to die."

Connie has taken steps to cocoon herself. She shut down her personal Facebook account. She blocked all numbers from her phone except her husband's. She has kept visitors to a minimum.

"I needed to minimise everything that could cause me stress," she said. Now stabilised, she is feeling much better than when she was admitted.

"It's turned out quite differently to what everyone expected. I don't know if I'll get to go home but if I do get to go home, it will be not necessarily to live. It'll be to go home to die peacefully, which is my ideal way to die," she said.

Her message to her community is clear.

"I'm still here," she said.

"Thanks for the overwhelming support. The presents, the flowers. There's literally nothing I need, so people can feel free to send their love."

She wants to try her own version of *Sadako and the Thousand Paper Cranes*, by collecting paper hearts, rather than cranes. They can be sent to her via Clare Holland House or her personal address at PO Box 498, Belconnen 2616. If they want to show their love, that's the best way to do it," she said.

Any kind of paper heart, with a message on it."

Talk of legacy sounds pompous around the down-to-earth Connie. She wanted to make a difference but didn't look beyond that.

"I've always said I wanted to prevent just one other family from going through what we're going through but I never saw that as a legacy and I still don't see anything I've done with Love Your Sister as a legacy.

"I do feel like I'm leaving something behind. It's a living organism now. It's got its own heartbeat. I don't think that my heart needs to be beating for the Love Your Sister heart to beat on. The Love Your Sister village will be beat on; it has started and it will continue. And I feel that with every fibre of my body.

"I think at the end of the day, if I have a legacy, it's my two children.

"I'm proud of the work I've done, I'm proud of Love Your Sister, particularly proud of Big Heart Project.

"The work is fun and it's exciting, it's a distraction from the negatives in my life. It's so life-affirming. And hopeful. If I could say one word that would encapsulate anything and everything that has been Love Your Sister while I've been around, I think it all comes down to hope. Because hope's a hard thing to hang on to sometimes.

"Cancer's such an insidious thing. It ruins so many lives and tears apart families. It's not just that it kills people, it creates divorces, it creates divides, it can split families in two.

"So the hope, I guess, is the lasting message for me."