

Choir soars above Dementia

Winter sun is streaming into the Hughes Community Centre as a group of mainly elderly people join hands, sway and sing the Vera Lynn classic, *Now is the Hour*. It's beautiful and moving and joyful.



The members of the Alchemy Chorus in full song. Picture: Hilary Wardhaugh.

This is how the Alchemy Chorus, a choir for those living with dementia, always finishes its Thursday gatherings, everyone brought together because of dementia, but trying to leave it behind as the music transports them for two hours (with a break for morning tea, of course, with tea and scones served on a table with flowers someone has brought from their garden).

David Cross is attending the choir with his father-in-law Frank Millburn, who is in a wheelchair and has dementia.

"He can't remember what he had for breakfast but he can remember all the words to the songs. It's an amazing transformation," Cross says.

The choir was started in 2016 by Brian Triglone, also the conductor, who was inspired by a similar one in the United States he saw on YouTube.



A supportive arm in the Alchemy Chorus. Picture: Hilary Wardhaugh

The choir is for people with dementia, their spouses, their carers, their relatives and volunteers. But it's not about singling out those who have dementia.

"It's including them in a community activity, not just one that they can do on their own," Brian says. "There's no sort of sympathy. We don't want sympathy. We can sing. We're a choir and everyone's involved in it."

The choir is called Alchemy Chorus "because it's a blending of things to come up with something beautiful", says Brian, who was awarded an OAM for his services to the choral community.

"I'm not sure why I chose dementia, other than it's everywhere," Triglone, 73, says. "Also we've seen what music can do for people with dementia. People with dementia can sing. They may not be able to converse much, but they can sing. As it's turned out, one of the needs the choir fulfils is inclusiveness. Once the dementia strikes and their partner starts to go downhill, they withdraw from society. It's awkward. It's difficult to explain to people. But they can come here and do something together and talk to other people in the same situation."



Photographer Hilary Wardhaugh and choir founder Brian Triglone (front) with members of the Alchemy Chorus. Picture: Jamila Toderas

"The theory is you should pick music that people knew in their late teens or early adulthood, so that's what we've focused on. But we've also found people can learn new music. And we're getting anecdotal evidence that it is helping people to do things. For instance, one lady who happened to die a few weeks ago, she'd lost the ability to use a knife and fork to eat, couldn't do it. But after choir, she'd go with her daughter to have a meal and be able to use a knife and fork."

Canberra photographer Hilary Wardhaugh's father Keith was in the end stages of dementia when he joined the choir, before he passed away two years ago. He was a renowned entomologist but dementia had reduced him to almost uncommunicative. Except when he went to the choir.



Photographer Hilary Wardhaugh. Picture: Jamila Toderas

"He'd sit there and mouth all the words. It was amazing. It seemed like he was asleep, but he wasn't. There was some level of consciousness," she says. "The type of dementia he had, he still knew who we were. He thought his room was his office and he'd stay in there all the time. Then he came here and enjoyed it. He loved it."

The choir sparked something in Wardhaugh

"When I first came here, I found it difficult to work out who had dementia and who didn't. Sometimes it's obvious. "Visually, I thought that was a really interesting thing to explore."



Choir members Stewart and Sheila Turner. Picture: Hilary Wardhaugh.

Wardhaugh spent the last two years documenting the choir, capturing candid shots and portraits of members, mostly couples, the love between them obvious.

She says it was a therapeutic and cathartic experience after losing her father to the insidious, incurable disease.

The portraits were about smashing perceptions.

"I wanted to photograph them side by side as if it was a wedding portrait or a family studio portrait and I did not want to inform the viewer which person in each portrait had dementia," Hilary says. "I want people to see that even though someone has dementia they are still the same person, they still have a story, just different."



Phillipa and David Kidd in one of Hilary Wardhaugh's portraits.

"Also because unlike cancer where someone may lose their hair or get jaundice, with dementia it is invisible, until the later stages. I want people who have never encountered a person with dementia know, that they can still treat, interact and talk to people with dementia the same way they used to. What they may respond with may be muddled up and incoherent, but that's okay. And not to be afraid. There's no need to speak in a patronising way, or loudly and slowly and no need to treat them like children."

The project has culminated in two exhibitions under the name Memories are Made of This, the first at the Weston Creek Uniting Church on August 31, when the choir will also sing, and the Canberra Contemporary Art Space in Manuka, opening September 5.



Choir members Glyn and Dawn McKay. Picture: Hilary Wardhaugh.

At the Manuka exhibition, the exhibition will be set up as a lounge room, with the photographs displayed above a mantelpiece. Snippets of the subject's life stories will be adorned on the walls.

"The funny thing is I collected some amazing stories from them and not one of them mentions dementia. Everyone has written several pages about their lives, not one of them mentions it," Wardhaugh says. "No one has told their dementia story. They've told their life story but not their dementia story and I thought that was fascinating. And I think it's a reflection on our society because these people don't want to be defined by their dementia."



Members of the Alchemy Chorus.

Dementia Australia defines dementia as not one specific disease but a collection of symptoms that are caused by disorders affecting the brain.

Dawn McKay, 81, holds the hand of her husband Glyn, 89, during the morning tea break as they speak about the choir. The couple live at the Goodwin Village in Monash. Cheeky and full of smiles, he has had dementia for seven years. In her ninth decade, McKay is still there for her husband of 63 years.

"I have to make sure I can be there to dry him and help him with his dressing, doing up his buttons and things like that," she says. "They're very slow at doing things. I think that's one of the most frustrating things."

"She beats me....," Glyn jokes, a spark in his eye.



Alchemy Chorus member Glyn McKay, 89. Picture: Hilary Wardhaugh.

"And it's interesting," McKay continues, with a smile. "People can meet Glyn and think he's fine and hold a conversation but if you're there for any length of time, he'll repeat the same thing, ask you the same thing. Don't you darling?"

"I keep forgetting," her husband says.

McKay feels she gets support from her family and other community groups but some days are hard. "We had a bad night last night," she says. "Glyn sometimes feels like he can't swallow and has a panic attack. There's nothing wrong. I used to teach preschool, so I go back to my preschool days and talk slowly and tell him to breathe. I sound as though I'm marvellously patient, but I get cross too."

Glyn McKay, who worked in industrial relations, and his wife, a now retired preschool teacher, met on a Queensland beach and seem as in love as ever.

"I couldn't have done better," she says.

They are original members of the choir.

"It's so uplifting. Glyn can't sing. I can't either. He's from a Welsh background, so he should," McKay says, with a laugh.

"Every Thursday when we leave, Glyn says, 'That was really good'. No one tries to outdo anyone. It's just a happy feeling. It's a marvellous group, it really is. Singing's good for the soul. And I think it's good for the brain, learning the new songs."

Above the hubbub of the choir's morning tea, Tom Anderson, well known as chair of the Weston Creek Community Council, talks about caring for his wife Margaret who has had dementia for 17 years. He's 74 and he's 73.

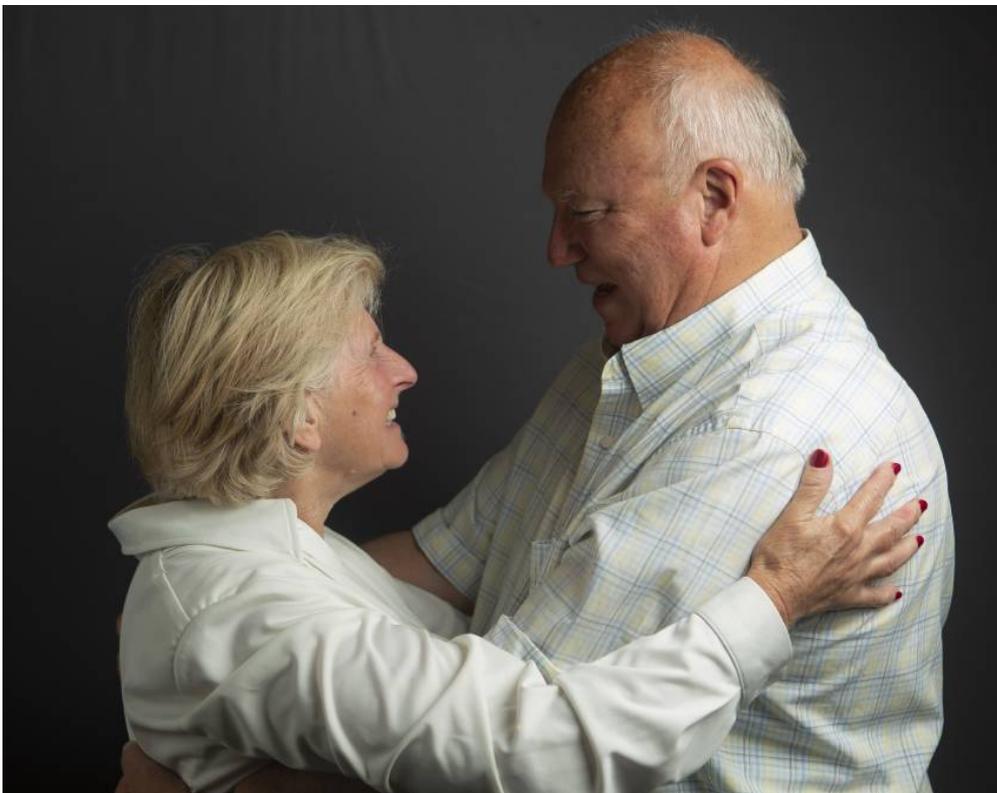


Choir members Margaret and Tom Anderson. Picture: Hilary Wardhaugh.

"There's slow changes as you go along. You notice a little drop as something's happened," Anderson says. "But the stimulation from carers coming into the home and the choir and other activities is amazing and it gives me a lot of relief.

The great thing about the choir is that you don't usually have carers come together, but, here, they come together and they all understand.

If they've had a bad day or a bad week or a bad month, we can talk about it. We can also talk about what services we get and where we're up to. It's a marvellous second tier for us the carers. And I still don't think Brian understands how wonderful it is for us."



Choir members Margaret and Tom Anderson.

"And the people with dementia talk to other people with dementia and the volunteers. It's just wonderful how it all works."

Anderson, who used to work in Customs, and his wife, a former teacher, have been married for 45 years.

"It's sort of part of the package," he says of caring for her. "If the situation was reversed, she'd do the same for me. It is what it is. You make adjustments. What's the alternative? We travel a lot. I don't want to be sitting in a chair, waiting. She still does things at home. Still puts the washing out, brings it in, folds it up. Nine times out of 10, I find it. Still cooks with me in the kitchen. All these things are important. You don't take away what they're capable of doing."



Choir members Margaret and Tom Anderson.

Brothers Peter and Gordon Scott also attend the choir. Peter, 79, is [described by rugby.com.au](http://rugby.com.au) as a "fast, skilful, naturally talented" centre who played rugby for the Royals and was a Wallaby in the early 1960s.

Gordon, also well-known for his involvement, at all levels, with Easts rugby, says his brother has been diagnosed twice as having dementia. Peter disagrees and thinks he is "just getting old". He still feels himself.

"I keep getting told my short-term memory isn't good," he says.

Gordon is Peter's "younger, bigger brother". They enjoy their together time in the choir.

"My father used to sing, my mother used to sing, the whole house used to sing when there was nothing else to do, so I grew up with it. Belonged to school choirs and it just seemed a very natural step to take [to join the choir]," Peter says. "As a group they're just wonderful, very supportive."



Brothers and choir members Peter and Gordon Scott. Picture: Hilary Wardhaugh.

Peter says having Gordon by his side means everything. "Exceptional," he says. "Since I've crashed, he's been there. I'm very lucky to have his support."

The cruelty of dementia is laid out bare in another couple's story, both preferring to be anonymous.

The wife speaks outside the choir room. As her husband's condition worsened. Their dream retirement on the South Coast came to an end and they have ended up living with their daughter and grandchildren, in a granny flat, back in Canberra.

Her husband, a retired academic, has been diagnosed for three or four years "but I reckon he's had it for 10 years", she says. He's 78, she's 74. They are physically fit but restricted by his mental decline and her many family responsibilities.

"I should be giving my husband a lot more care, patience, understanding but instead he's forced to pitch in and help with everything, which is probably good for him, in the long run," she says. "He's got to empty the dishwasher, he's got to chop the carrots for dinner. Whereas, other men with dementia, they're sitting there being waited on by a doting carer."

The choir gives her some respite.

I want people who have never encountered a person with dementia know, that they can still treat, interact and talk to people with dementia the same way they used to.

Hilary Wardhaugh

"People with dementia are very happy when they're out there doing things. They're a different story at home," she says. "I get to see all the other wives and partners and carers and we can all give each other a little bit of shoulder to lean on."

Because it is tough.

"I feel absolute resentment. Ripped off," she says.

"I'd probably be camping around Australia if I was on my own having a lovely time, but you can't really. I feel very, very ripped off. Especially in those four or five years when someone is coming down with dementia, that no one is aware of, what is happening to your life".



*The choir members join hands at the end of every session and sing Vera Lynn's Now is The Hour.
Picture: Hilary Wardhaugh.*

"They're just contrary and difficult and if you want to do something, it's a big effort. I haven't got this partner I can say to, 'Let's go snorkeling' or 'Let's climb a mountain'. I have to inspire him, whereas, once upon a time, we inspired each other. "He's not a bad guy. It's the dementia. And when you've got something like the choir that someone else has organised for you and you can just sit back and enjoy, then that's really good."

The sound of the choir singing Leonard Cohen's *Hallelujah* next door washes over us. It's a moment of peace amid the turmoil this woman is feeling. She gets up and goes back in to the room. Back to her husband.

- **Memories Are Made of This** by Hilary Wardhaugh will be at the Canberra Contemporary Art Space in Furneaux St, Manuka from September 5 to 15.
- All prints will be for sale and 100 per cent of proceeds will go to Dementia Australia.
- The exhibition will also be at the Weston Creek Uniting Church on August 31 when the Alchemy Chorus will also sing at 10.30am.

Article by Megan Doherty, The Canberra Times, Sunday 4 August 2019, accessed at <https://www.canberratimes.com.au/story/6309622/the-choir-that-soars-above-dementia/?cs=14264>

