



Preparing
the Way



Meet Jo Fuller, death doula on the art of dying better

SA Weekend The Advertiser ~ October 16/17, 2021 ~ Penelope DeBelle ~ Cover Story "Dying Better" with Jo Fuller ~ Inside the Life of a Death Doula

A doula is someone we associate with bringing new life into the world but, increasingly, they're helping people leave it, too. Meet Jo Fuller, the Adelaide death doula helping people cross over.

He was elderly and unwell but had shrugged off serious illness in the past. More than a decade earlier he had been on dialysis until his wife donated a kidney. It gave them 11 more years together.

But after a mini-stroke and myriad complications that drugs could no longer resolve, there were no more rabbits to be pulled from hats.

Aged 74, his liver was failing. "That's it," he told his family, "I've had enough." He was in an Adelaide private hospital and his wife, who asked not to be named, gathered the family around, including their son and daughter.

She also called in Jo Fuller, an end-of-life doula based in Adelaide.

As the man faced his death, he spent a day going into details with them about the kind of service he would like and the cremation he wished to have. "Dad made it very clear early on what he wanted to do, where his service would be, what he wanted," says their daughter. "He made his wishes very clear to my brother, Mum and I."

Then the dying man's brother arrived. They hadn't been close but he and his wife had moved to Adelaide and the families had seen more of each other since then. He had firm views about what should happen, namely an Adelaide burial although the family was from Sydney and wanted it there, and in a church. The man's wife and children were stunned.



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“He just sort of burst into the room and said (the dying man) was married in a church and was christened in a church and should have his funeral in a church,” the wife says. “It was just so distressing that someone would come in and say that when we’d spent the whole of Sunday discussing with (him) what he wanted to happen.”



Jo Fuller, a Death Doula who guides people through the process of dying, at Adelaide’s West Terrace Cemetery. Picture Matt Turner

It was a clash of beliefs from opposing trenches in a situation where emotions were already painfully heightened. The brother was also very unimpressed to learn a doula was on the scene, a role he knew nothing of and had little time to understand.

Tensions rose and by the time Fuller walked in she was met with a full-on family fight around a deathbed. The first thing she did was to suggest they all leave the room. “I asked them to take it out of there,” Fuller says. “I said, ‘He can hear you all arguing’.”

In a private room, Fuller sat them all down and explained that the man’s wife and children had been in detailed discussions with the dying man and that they were representing his wishes, not theirs. It was about what he wanted, no one else.

The anger leaked out of the room. Confronted with an explanation and context delivered by a third party, the brother could see what was going on and changed his tone completely, accepting this was the man’s choice to make.

“He completely backed off,” the daughter says. “Jo really took the heat out of it.”

Each death is different but it is becoming increasingly common to have in the mix an independent third person, a doula, who can discuss options, support, guide and advocate for the person dying and/or their family.

As Fuller explains it, doula is a Greek word for woman servant, and the term has been refashioned to mean a person of service; so a birth doula can assist at a birth and a death doula is there to serve the ageing, ill and dying in a non-medical support role.

Fuller prefers calling herself an end-of-life doula because she often comes in after a diagnosis and well ahead of a person’s death, while they are living with incapacity or terminal illness.

But she isn’t afraid to talk about death. “I am happy to say die, that a person has died, they haven’t passed away, you haven’t lost them,” she says.



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“People don’t want to talk about death and dying, they don’t want to say those words, there is a real and genuine fear associated with them and it is time we became more at ease. We are all going to die at some point, it’s a 10 out of 10 stat!

The point at which you would engage a doula, a paid professional with non-medical qualifications, depends on you.

Fuller has a client, a woman with a degenerative neurological disease, who she will help at stages along the way and will be with at the end.

A doula may or may not be present while the person is dying; in the man’s case she was there for his family but at other times she is there to literally hold the hand of a person on their deathbed, to be there for their last breath and to make sure that their wishes about the manner of their death are upheld.

“If you’re very fortunate you come in at the very beginning,” Fuller says. “Someone might be not well, so it’s not just about dying, it might be a life-limiting illness.”

Control, capacity and choices diminish or disappear as a person dies, and hiring a doula can be one way of making sure their preferred choices are known.

Before the end happens, Fuller is careful around language too, so people don’t define themselves as having a terminal illness because it can limit how the world sees them, and how they see the world.

“You’re still a person,” she says. “So we train our doulas to be careful of the language they use because that empowers a person; they are living with a diagnosis and may not be well but it’s not just about dying.”

The job is a very practical one. A doula will guide the dying through the documentation process, making sure they have a will – 45 per cent of people still die intestate – and that they know who their executors are.

They will help them make end-of-life medical care directives, with decisions on whether to be buried or cremated, about who they want with them and where they want to be, at home, in palliative care or in a hospital. Once these decisions are in place, the doula can advocate for them to medical staff and make sure their wishes are followed.

“I ask them, ‘What do you want?’,” Fuller says. “A doula doesn’t provide advice; it’s a non-medical role and it has nothing to do with medication or telling people to stop treatment. We offer choices and we support them. It’s like walking alongside them; it’s their journey.”

SPIRITUAL BELIEFS

In the dying man’s case, Fuller also helped in another way. The hospital where he became ill was not a palliative care centre and once he decided to refuse treatment, the family thought of moving him to a hospice equipped to manage the final stages before death.

But he quickly became sicker and was in so much pain they decided he should stay. A day or so in, the family worried that he was suffering too much and wanted him made more comfortable.

Individual staff were doing what they could but they had no master plan for managing him as he died. “Jo talked to the nurses about ‘how can we increase pain management and how can the family let you know when they think help is needed?’. That opened up the conversation,” his wife says.



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“She managed all that for us. We were already devastated and we didn’t want to be leaving his side.” Fuller says she made sure she stayed in place until the pain issue was sorted. The medical mindset was still to keep him alive and hadn’t switched over to palliative care – which opens the door to administering drugs like morphine which are not safe for long-term use.

“Even though he was waiting to die, the family knew it, everyone knew it but it wasn’t clicking in,” she says. “Their medical training is all about keeping someone alive.” After her intervention, he was given a morphine pump on Monday and died on Wednesday night, comfortable and sometimes conscious as his life ebbed away.

Fuller, who converted to Catholicism at 17, has strong spiritual beliefs, including in miracles and in an afterlife, but she calls this part of her own self-care rather than a feature of her doula practice. She isn’t looking to make deathbed conversions.

“We have to be very careful about our own beliefs and values and we train our doulas to have that at the back of their minds,” she says. “Our role is to just listen and talk. We are walking alongside them, holding space, supporting them, facilitating whatever it is they want to happen.”

Buddhists in particular, who throughout life embrace dying as part of a karmic cycle, have for a long time offered a doula service that focuses on helping the dying towards a meaningful and peaceful death.

The doula isn’t there to preach or convert but to bring to the deathbed a spiritual practice that embraces death as natural. “The caregiver stays calm in order to allow others to fall apart, because sometimes falling apart is what we must do,” Buddhist teacher and author Sallie Jiko Tisdale writes of the role of a doula.

Australian-US lawyer and author Dr Sarah Krasnostein in her most recent book, *The Believer*, made a moving connection with a Tibetan Buddhist, Annie, who sat with people as they died and managed the logistics of their death, which sometimes included a living wake. Krasnostein found the experience confronting and sad, but also very physically and emotionally demanding for the doula.

Fuller says there are doulas training at the Preparing the Way training school who meet the client’s needs, including a Zen monk, and a doula in Melbourne who supported a woman who died in a nursing home and wanted a spiritual cleansing ritual carried out.

It is more of a calling than a job. Fuller started out a country girl from Gundagai in NSW, surrounded every day by farmyard birth and death.

She studied nursing and remembers being struck when she was still young by what a privilege it was to be with someone as they die. After leaving nursing and working in pathology she did an apprenticeship in electrical engineering before working herself up into a management position at Telstra, becoming the SA and NT manager for Managed Infrastructure Networks.

CRASH COURSE

She left Telstra at around the same time her then partner, Debbie, brought her dying brother Adrian and his family to live with them in Adelaide. He was only 37 and had been diagnosed with a brain tumour and would be leaving behind a wife and baby. His family moved in and were constantly there, playing cards or Scrabble while Adrian slept or sometimes woke and spoke with them.

This was Fuller’s crash course in caring for the dying and she would sleep on the couch nearby just to keep abreast of his medications. Something woke her in the early hours one morning and she went over just as he died.



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Debbie says she looks back on losing her brother as a time when her whole family bonded closely, including her parents who came from Mt Gambier to spend every minute with him. “As sad and devastating as it was to watch and wait for the youngest of our family to die, we did so knowing that he knew we were there and he was surrounded by love,” Debbie says.

Fuller wasn't a doula yet but she had found her calling. “It was Jo who slept in the lounge that night and witnessed Adrian's last breath,” Debbie says. “After checking his pulse, she calmly woke his wife who had fallen asleep in the chair beside him while holding his hand.”

Death doulas can be seen as a Byron Bay thing, something for alternative lifestylers committed to home births and living off the grid. In fact, it is an old practice that is gaining in popularity partly because of what Fuller called the silver tsunami of baby boomers who are reaching the end of their lives.

Surveys show that 60 to 70 per cent of people would prefer to die at home compared with only 14 per cent today who manage to do that. There isn't the capacity for the current ageing population to be accommodated in the available palliative care hospices, and that growing awareness is encouraging people to bring in doulas to safeguard their own quality of care at the end.

It can take up to 16 people to support a person at the end of their life and Fuller says a doula can pull those people together, whether at home or in a hospice.

Fuller, who trained with Preparing the Way and works as an educator with them, doesn't like to talk about good deaths because, like a bad death, it passes judgment on the experience.

“I spoke to a woman a few weeks ago and her husband was in pain right up until he died and it was very distressing for everybody,” Fuller says. “If she knew, she would have advocated more and if I had been his doula, I would have done things a lot differently but that was his journey, that was the experience.”

PROFESSIONAL

Inevitably, the presence of a doula at a deathbed can ruffle feathers, particularly within the medical profession, some of whom see doulas as another body to get in the way.

Fuller says attitudes vary a lot and some nurses tell her they welcome having doulas with patients. But getting them into hospitals can be difficult, even though their job is to bring in the palliative care team, doctors and specialists to carry out the patient's wishes.

“One of the issues we've got is that a lot of people see us as hippies, a New Age thing,” Fuller says. “But our training is very professional.”

Preparing the Way, which Fuller is part of, has just been accredited to offer certified end-of-life doula services and they hope by next year to be recognised as a registered training organisation.

Engaging a doula in readiness for death, yours or someone close to you, is a way to reclaim an acceptance of death that earlier generations seem to have shut out. It wasn't done to talk openly about dying as an event that needed to be prepared for, and it has left many people stranded in silence about what should be done when their time came.

“We have outsourced death and I'm not sure why we've done that,” Fuller says. “I remember my grandparents talking about their family and how they cared for the body in the parlour and people came over and the wake



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lasted for days.” Today, people are under the impression that as soon as someone dies, the funeral director must immediately come in and whisk the body away.

Fuller says that is not the case and keeping the body at home can help some families to grieve.

“You know you can have the body with you for five days if you want to, so long as it’s cooled and cared for properly,” she said.

“People forget they have choices and can have their preferred death at home.”

Letters to the Editor SA Weekend October 23/24 2021

Letter of the Week

Penelope DeBelle’s sensitive feature on death doulas should be required reading for religious zealots and medical professionals (The Art of Crossing Over, Sa Weekend, Oct 16-17)

Adelaide doula Jo Fuller says she asks dying people “What do you want?”

In stark contrast, the focus for medical professionals and the devoutly religious “is all about keeping someone alive”.

But as The Doors frontman Jim Morrison snag on Five to One: “No one here gets out alive.”

Should my own prognosis be painful and terminal, I would rather a doula who respected my wishes than a doctor who was duty-bound not to.

Bernie Coates, Modbury North

The final goodbye

I found your article on a death doula (The Art Of Crossing Over, SA Weekend, Oct 16-17) quite interesting. I didn’t know that they existed.

I brought my partner home to die in 2013 after he was diagnosed with a stage four brain tumour. WE received help from palliative care and the royal district nurse. A lot of what was in the article we did at home.

When he passed at 1am we went to bed and slept and the next day notified everyone and were able to keep him at home for 12 hours which enabled friends and family to say goodbye.

Glenis Jones, Newton

Doctors need training

I was touched by the story of Jo Fuller, an end-of-life doula who provides support and guidance to those facing a terminal illness and their families. I know some other doulas, although they do not use that name.

They are palliative care doctors and their helpers, and their role is vital in ensuring that the end of life is as mentally, physically and spiritually pain-free as possible.

The tragedy is, Jo Fuller has found, that many doctors have received inadequate training in this area.

I can only hope they will be willing to learn from people like Jo.

Roslyn Phillips, Tea Tree Gully