

Meet the doulas helping the terminally ill face death with a smile

They are best known for providing support during childbirth, but doulas are increasingly there at the end of life, too. By Hanna Hanra



Barbra Bird, who has terminal breast cancer, hired the services of Sam Hill (left) ORLANDO GILI FOR THE SUNDAY TIMES MAGAZINE

The Sunday Times, April 7 2019, 12:01am

‘When you die, I think that your consciousness goes with you and your energy dissolves back into nature,’ says Barbra Bird, a 46-year-old artist based in Hastings. ‘And that’s as complete an answer as I can give right now.’ In April 2018, Barbra was told that her rare and aggressive form of breast cancer had returned and spread to her bones. She was given a year, perhaps two, to live. ‘I was never really a healthy person,’ she says, ‘but it totally blind-sided me.’

She knew she wanted a doula to help her navigate death, having previously read about end-of-life companions while rooting around on the internet. The idea had stayed with her. With her family in America, and having only recently relocated from London to Hastings, she had few people she could turn to in her community for support. ‘My husband and I were in a place where we didn’t know anyone. We were on our own with this huge revelation to deal with,’ she explains. She found an organisation online called Living Well, Dying Well, and filled in a request form. ‘It was a relief to know that we didn’t have to figure everything out on our own,’ she says.

The word “doula” is derived from the Greek word for “servant woman”, but now refers to a person providing companionship and support. Today, doulas are usually associated with childbirth — specialist companions employed by pregnant women to help them during and after labour. Unlike midwives, birth doulas do not perform clinical tasks — instead, they provide spiritual, physical and emotional care.



Sam helps Barbra with the coffin she has made and decorated ORLANDO GILI

Death or end-of-life doulas are similar in that they support family members and loved ones at a time of heightened psychological and physical need. The movement has caught on, following a pioneering volunteer programme in New York in 2000 that paired doulas with terminally ill people.

Barbra’s doula, Sam Hill, had studied for a degree in forensic science. “It’s a different angle, but it helped me find my path. I’ve never had any fear around death,” she says. The roles of doulas vary according to the client’s wishes. Some act as carers, visiting daily to help the person wash and dress; others offer emotional support, talking through the meaning of life and death.

Barbra met her doula a month after her diagnosis. “We didn’t quite know how to start. It’s been a learning process, but Sam is really good at picking up on what I need emotionally and in terms of support,” she says. Sam charges £12 an hour and visits Barbra at home, or will accompany her to doctor’s

appointments. “It’s good to have an impartial ear so you can zone out,” Barbra says. Though end-of-life doulas are secular, the pair often talk about what happens when we die. “It’s interesting to philosophise about what could be out there,” Barbra says. “And that has made it easier for me to talk about my own death.” When people ask, she describes her doula as a midwife that she’s hired to accompany her on her way out.

Sam has even joined her at the Coffin Club in Hastings, which helps people plan their own send-off, and where Barbra has spent time building and decorating her own coffin. “We talk about how we want our weddings but not our funerals. Death can be scary and I don’t think that is the way it should be. It should be a celebration of the person’s life.”

In Manchester, there is a funeral parlour that will pair you with a doula, and in Dorset there is Soul Midwifery school, which teaches practitioners how to ease the passage of dying. The death doula movement is growing in the UK, in demand by an ageing population who are articulate about their healthcare needs and often cannot depend on family members to act as caregivers. There are 220 hospices across the country, providing care and support for about 220,000 dying people each year; however, it is estimated that a further 100,000 people a year who would benefit from hospice care are missing out. Furthermore, a report last year revealed the extent of the crisis in social care — at any one time, there are 76,000 vacancies in the care-working sector in England.

Having someone by your side as you die is a luxury, but it shouldn’t be. While birth doulas are seen as something that only affluent yummy mummies can afford [a typical birth doula package costs £800-£2,000], death doulas are keen to ensure that they are available to anyone. While some charge, many also work on a voluntary basis alongside charities and in hospices.



Li Mills (left) and Jo Giles (right) trained as end-of-life doulas with Hermione Elliott, in Lewes ORLANDO GILI

Hermione Elliott set up Living Well, Dying Well in Lewes, East Sussex, in 2009. The former nurse, midwife, therapist and palliative caregiver experienced three deaths in her family, each a unique glimpse into the experience of dying. Her infirm father collapsed at home and the emergency services had tried to resuscitate him. “I was shocked to the core that they thought this was the right thing to do to a frail, elderly man,” she says. Her aunt had a series of invasive medical interventions before it was made clear she didn’t want treatment. In contrast, Hermione’s mother had “an absolutely beautiful” death at her nursing home. “She asked my permission to die, and I supported her in that. The GP understood and gave her some pain relief, and three days later she died. It was an exquisite experience,” she says.

Hermione realised there was a need for end-of-life caregivers, not healthcare professionals but ordinary people trained to support the dying and their families. She developed the UK’s first training course for end-of-life doulas, certified by Crossfields Institute, a charity and not-for-profit company that supports education providers. The 20-day programme combines practical training, such as how to fill out a death certificate, with theory surrounding the psychology of death, including an examination of grief, emotional responses, palliative care, socio-legal requirements and the soul’s journey.

Through Living Well, Dying Well, Hermione has trained more than a hundred end-of-life doulas. Most people who enrol are women, often from caregiving backgrounds. She estimates that more than half of those who complete the training are in practice, with others applying the skills to their existing professions. Hilary Peppiette, for example, returned to her job as a solicitor in Edinburgh after her training, and now the law firm she works for is the first in Scotland to offer specialist counselling and support to clients facing their final days.

Over a series of three-day sessions, trainee doulas learn what to expect during the last few months of life. “But they are not the experts,” Hermione says, “and we never assume to say that we are. However, we may be a few steps ahead of the family in terms of our knowledge and understanding.”

Trainees are encouraged to find voluntary experience, approaching hospitals, hospices and individuals that might be looking for help. Carole Walford, chief clinical officer at Hospice UK, says end-of-life doulas have an emotional and practical responsibility: “The psychological support is enormous, but they are also a good guide through the complex clerical stuff.”

The first thing a doula will do is help their client write an advance care plan. Part of this will address their medical wishes relating to refusing specific treatment, for example heart resuscitation or being put on a ventilator. This acts as a legally binding document in case they are unable to express their wishes themselves. The medical impetus is to keep people alive, but intervention can be painful and distressing, particularly for those who are elderly or have a terminal illness. The other part of the plan maps out more personal wishes. “If something happens and I wind up in a hospice, the plan can be as detailed as ‘Don’t feed me melon or play country music, and make sure my cats are with me’,” Barbra says.

The document is a useful tool to start a wider conversation about death. “There is so much about dying that is not talked about or understood,” says Tree Carr, who has been a doula for three years, based in Margate. One spring morning in east London, she noticed a man in the street wobbling on his feet. A knowing feeling came over her and she reached out to help him to the ground. His face changed colour, and two minutes later he had died. She spent the rest of the day comforting his family, who had been walking ahead.

It wasn’t the first time she had been with someone in their final moments. As a teenager, she witnessed a motorcycle accident and the driver had died in her arms. She was moved to do more. “I found the Living Well, Dying Well website and signed up straight away,” she says.



Tree Carr, a doula from Margate: “In the end, people realise that life is about relationships” ORLANDO GILI

Tree believes we are now so far removed from the dying process that it has become taboo. In the past, people were more likely to die at home with the whole family present than in hospital. When the person had died, their body was washed, their hair brushed and mourners would spend time with the deceased at a wake. There was a sense of closure. “It helps with the grieving process if you can see the body and pay respects,” Tree says.

“All my Irish friends have been to a wake,” says Dr Ollie Minton, a Macmillan consultant in palliative medicine at Brighton and Sussex University Hospital. “But in Britain it is unusual for someone to see the body of a loved one or neighbour once they have died.” He believes that our attitude towards death could easily be reshaped. “There have been a few celebrity deaths and storylines in soap operas that have helped people talk about death. But the best thing would be for death to be taught in schools, like sex education. People should be able to have a conversation around the dinner table about what they want to happen to them when they die, or make a note of it and tell their families where to find it on their laptop.”

In a society obsessed with youth and living for ever, death isn’t just hard to talk about, it can also be hard to accept. “I was at a vigil for a very old woman, and her daughter kept saying that she didn’t want her to die,” Tree remembers. “It was almost as though her energy was keeping her here. There was some

forgiveness towards each other that had to happen. And once that had taken place, the mother said she felt a physical weight shifting, as if the emotional burden was released. She died a few hours later when the daughter had left the room. A lot of people realise on their deathbed that life is about relationships and love. It sounds like a cliché, but I think people do realise that in the end.”

Jo Giles and Li Mills both graduated from the Living Well, Dying Well course last year. They visit the same woman who needs round-the-clock palliative care. The two share the work with a number of other carers and keep track of her wellbeing, both physical and mental. “The person we are supporting is frightened of dying and being in pain,” Jo says. “It eases her anxiety when she has a good connection with the doula, who can listen and be alongside her.”

Li also works in Brighton at a drug and alcohol outreach programme run by the charity Equinox. Late last year she worked with a homeless person who was dying in a hostel. “He talked about his life’s regrets and we made some plans to contact his family,” she says. “He wanted to put his affairs in order and write a few letters of apology.” The man died before the two could meet again, but Li believes that being able to talk about his death and make plans allowed him to let go. “You can’t tell when you form these relationships how long they will last,” she says.

So what does it feel like, to journey with someone to their death? “Of course it is sad when we lose people, but when you are guiding someone there is a sense of amazement,” Tree explains, lifting an imaginary glass into the air. “You almost want to toast them. ‘We did it. Bon voyage, you’re going into the great mystery.’”

To learn more about Living Well, Dying Well, visit lwdwtraining.uk