



When fantasy writer Sara Douglass wrote a very personal blog about the way we deal with the dying, it sparked an unexpected conversation about society's taboo of death.

STORY: SHERYL-LEE KERR



AUTHOR SARA DOUGLASS IS DYING. OVARIAN

cancer. She feels grumpy and guilty. No, she doesn't know how long she's got – so stop asking. She's tired, too. All the time. So don't visit for a "nice cuppa" – it just makes things worse. And stop with the empty platitudes. Who are you trying to make feel better here?

Sara Douglass has written 18 novels – her most recent, *The Infinity Gate*, has just come out. She's also penned two non-fiction books and is squeezing out a 19th novel between her exhaustion and cancer treatment.

The former nurse and one-time lecturer in medieval history lives alone in her home in Tasmania, surrounded by her beloved gardens.

For years this self-described "very eccentric antiquarian" has blogged about her life, rattling around the kitchen and rustling about the garden beds.

"I love gardening deeply, as also the arcane arts of preserving," she says. "I am a great homebody, stirring pots of pickles while peering through obscure books and documents.

"I moved to Tasmania because I love the island, its climate and its beauty.

"It is a beautiful, isolated, eccentric kind of place and I fit right in."

But now this 53-year-old's whimsical blog, nonsuchkitchengardens.com, has garnered attention in a way she never expected. That's because last month she penned the truth about dying as she saw it – a no-holds-barred rage against the societal taboo.

She wrote about the pressure on the dying to make the well feel better. There were the empty gestures and seas of soft toys. The guilt and the efforts to suffer stoically.

And she didn't pull any punches.

"I am sick of being exhorted to be silent and sweet and stoic," she writes.

"I am sick of comforting people when all I want is to be comforted.

"I am sick of being abandoned by people for months on end only to be told eventually that 'I knew they were thinking of me, right?'"

After her post appeared, the floodgates opened. Instantly readers, fans, and strangers began to reply, posting their confessions and epiphanies, mea culpas and agreements.

While it wasn't the first time Douglass has mentioned dying in her blog, this post, so raw and uncensored, touched a nerve.

"The Silence of the Dying blog was initiated when an acquaintance told me I had no right to complain about anything," she says.

"I was so stunned by that it made me think of the wider implications, and about how silent and uncomplaining we – the chronically ill, the terminally ill, cancer sufferers – are supposed to be. It puts tremendous pressure on the person who is suffering.

"Anyway, The Silence of the Dying blog was

a cathartic exercise, working out a few issues in my own head and making sense of them."

She believes society is emotionally stunted on the subject because "the medical profession has now taken sickness and suffering and death out of the family home and put it into a hospital behind closed doors. People simply don't come into contact with it now".

And neither do most people know how to really help the sick or the dying. Douglass writes of reading a forum board post asking how to help a member who was undergoing a massive surgery that would incapacitate her for months.

"I suggested that if one among them, or many taking it in turns, could promise this woman two hours of their time every week or fortnight for the next few months, then that would help tremendously," she writes.

"In this two hours they could clean, run errands, hang out the washing, whatever. And they had to do all this while not once complaining about how busy their own lives were, or how bad their back was, or how many problems they had to cope with. Just two hours a fortnight, >>



FANTASY WRITER SARA DOUGLASS.

with no emotional-guilt strings attached. Bliss for the incapacitated or chronically ill.

"But that was too difficult. Instead, the poor woman was buried under a mountain of soft toys, dressing gowns, bath salts and bombs, daintily embroidered hankies, a forest's worth of Hallmark cards, chocolates and flowers and exhortations that everyone was 'thinking of her'.

"None of which helped her in any way, of course, but all of which assuaged the guilt of the gift-givers who mostly promptly forgot her and her daily horrific struggle."

The other common salve is to pay someone a visit. Not a useful one – involving cleaning or food delivery – but a social call.

"Lots of people always want to do the 'visit thing'," Douglass tells one blog reader.

"Have a cup of tea and a chat. For someone who is very sick, that is exhausting for them. The well can't understand how the very ill find holding a conversation utterly, totally impossible to maintain.

"Having a cup of tea and a chat' involves me having to get up out of bed, making someone a cup of tea (this is exhausting!), feeling as though I need to drag myself down to the shops for some biscuits or pastries or something, sit there men-

tally exhausted while someone chats cheerfully on and end up in a fair bit of pain by the end of it.

"While on the one hand company is good, on the other hand it is so appallingly physically and mentally debilitating that it can do more harm than good. We're trapped. Because I live alone I don't have anyone to act as gatekeeper for me.

"I have to be the bad guy and say 'This is too much, please leave'. And of course then people get offended, fluff off in a huff, and you never see them again."

Or worse, Douglass writes, is that the sick and the dying often wind up comforting the well and the undying.

"When first I was diagnosed with cancer I found myself having to comfort people when I told them I had cancer," she writes.

"In the end I just stopped telling people, because almost invariably I was placed into the bizarre situation of comforting the well by saying everything would be all right – which, of course, it won't, but that's what people needed to hear to make them comfortable about me again."

As for her legacy, Douglass says she doesn't care about being remembered.

"Whatever happens, I don't want to be mythologised," she says. "Many people are mythologised once they are dead, even if it is only within their own family.

"I remember being raised with the ghosts of numerous ancestors. My family were – and to a large extent remain – great ancestor worshippers. I always found that tiresome."

The author notes that in pre-Victorian times, society was at ease with suffering, comfortable with death and it wasn't "shunted away out of sight" from either adults or children. Grief was not subdued – in fact, it was embraced.

Today her greatest wish is that "dying might become a community event again".

"I can't see that happening," she says. "It shouldn't be celebrated, but it would be good to see it become a natural part of daily life." **STM**



AN EDITED EXTRACT FROM 'THE SILENCE OF THE DYING' BLOG

Two years ago I was diagnosed with cancer. Now everyone wants a date, an answer to the "How long have you got?" question. I don't know. I'm sorry to be inconvenient. I am not in danger of imminent demise, but I will not live very long.

As a society we don't tolerate chronic illness very well. Our collective attention span for someone who is ill lasts about two weeks. After that they're on their own. People grow bored with you not getting any better and just drift off. Phone calls stop. Visits stop. Emails stop. Eyes glaze when you say you are still not feeling well. Who needs perpetual bad news?

The end result is, of course, that the sick simply stop telling people how bad they feel.

As a registered nurse for 17 years I have seen scores of people die. I have watched the dying keep cheerful and reassuring while their family were there, only to break down and scream their terror when the family have gone. The one thing they all said, desperately, was "Don't let me die alone". But mostly they did die alone, doors closed on them by staff who were too frantically busy to sit with them, and relatives who have gone home.

I want to die at home, but I am realistic enough to know that my chances of that are almost nil. That is the death that awaits many of us. It is the way we have set up the modern art of death.

I am tired of the discomfort that surrounds the chronically and terminally ill. I am tired of the abandonment. I am tired of having to lie to people about how I am feeling just so I keep them around. I am tired of having to feel a failure when I need to confess to the doctor or nurse that the pain is too great and I need something stronger. I am tired of being made to feel guilty when I want to express my fear and anguish and grief. I am tired of keeping silent.

I promise to be more stoic in future. But just for one day I needed to break that silence.

➤ Read Sara Douglass's full blog at nonsuchkitchengardens.com/wordpress