Wish me luck as you wave me goodbye

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Rachael Dixey looked after her civil partner Irene after she was diagnosed with early-onset Alzheimer's disease in 2004. After Irene's death nine years later, Rachael gathered together diary entries and her reflections on their experiences into a book: *Our dementia diary: Irene, Alzheimer's and me*. In this article Rachael reflects on the slow, ambiguous and multiple losses that come with a diagnosis of dementia.

Irene had a gift for making people laugh, so at her funeral, at that breath-stopping moment when the coffin starts to glide away for the final time, we played Gracie Field's exuberant song 'Wish me luck as you wave me goodbye'. It had the effect of creating smiles and even some laughter in the full crematorium.

Everyone knows the phrase 'Time Heals' but I don't really know what it means, and I prefer the phrase 'Time Changes'. Healing implies that something clears up, like a grazed knee, but bereavement leaves scars of various shapes and sizes, and I liken it to one of those trees where barbed wire has been put too close, and so over time, the wire grows into the tree. Or rather, the tree grows over the wire, incorporates it, so that eventually it can't even be seen. But it's there.

People also say 'What doesn't kill you makes you stronger'. I'm not sure about that either. I remain, but my heart feels more fragile; things get better and I know that sadness can exist alongside happiness, but sometimes I want to say, in my interactions with others, tread carefully, for you tread not only on my dreams but on my sore heart.

In my more fanciful moments, I believe that the reason I was put on earth was to be with Irene so that I could be by her side through her diagnosis and death from early-onset Alzheimer's. This whimsy means that sometimes I'm not sure what the meaning and purpose of my life is now. I do feel that Irene and I were meant to be together – we knew that soon after we had got to know each other in 1980, me still a student at 26 and her a slightly older English teacher. Some couples do appear destined to be together – they know as soon as they clap eyes on each other, are married within weeks and remain devoted till death. This is romantic, but it happens. I thought we would spend all our lives together too; in the end, we had 33 years as a very 'couply couple' before Irene died aged 66. I still feel the presence of an absence, still feel as though I've been cut in half. I wonder if twins feel like this. I know many of the widowed do.

It's now three years since Irene died. Well, three years, five months and eleven days. But given the slow pace of a death from Alzheimer's, it's also been nine years since Irene 'went into care', five years since she was no longer able to walk and a whopping twelve years since we were told, one bleak April day, that the only explanation for Irene's symptoms was 'early-onset Alzheimer's'. Plenty of time for the wire in the tree to be buried deep inside…

Mine was a slow, ambiguous loss, the most painful landmark in its slow trajectory being the day Irene was admitted to hospital, never to come home again. This was the death of our domestic life, of small intimacies, of waking up together, of being the last face each other saw before we fell asleep. The Alzheimer's had reached a crisis point, Irene moving in and out of a paranoid stage. Once I had reluctantly agreed to her being admitted, as I thought for a few weeks, it became clear that living at home would no longer be a viable option. She was 60, I was 53. I was working four days a week to bring in the money, and had been looking after Irene for the rest of the time, helped by a rota of carers, all of whom now felt unable to manage. Crisis time indeed. The full story is in the book if you want to know it.

I don't know what Irene would feel about being the subject of a book and I have felt conflicted about making her, and our story, public. I haven't told the worst things that happened when she was in the throes of dementia. Irene was a less private person than I am; you knew exactly what she was thinking or feeling, whereas I have put myself through agonies at exposing those aspects of grieving that are normally kept behind closed doors. I'm aware that my persona in the book is the private me, the one that doesn't

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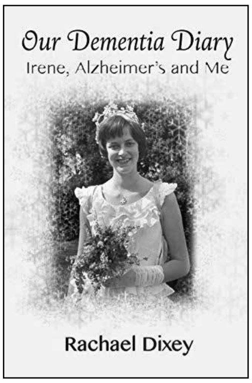
usually get aired in public, the red-eyed me that normally gets tidied up before emerging. But I also know that this very public, published story of grief and mourning, warts and all, is what makes it authentic and that has reached out to others. Irene would certainly want a story about a same-sex couple to be told. She was adamant about the importance of coming out, even at a time, in the 1970s and 80s, when you could lose your job for being gay. Despite the extraordinary turn around in social values (from Clause 28 to a Tory government legalizing same-sex marriage all within 30 years!), we are still somehow silent, missing. I've only ever heard one dedication for a gay partner to another on a phone-in request programme on Radio 2; I've only ever come across one other lesbian couple who experienced the same loss, to early-onset dementia. Unfortunately this other couple lived in New Zealand, a trek I actually made, to meet the surviving partner. Irene and I are a minority within a minority. The spaces minorities occupy can be lonely ones. There are many people who know I've lost my life-partner but don't think of me as a 'widow'. They cannot think of us as being just the same as them.

Was writing the book cathartic? I'm often asked. I don't really know. It was at the time, a way of someone like me, who doesn't wear my heart on my sleeve, to externalise some of it. There's a motif in our modern culture, of the importance of 'letting it out', a corrective to the way of the past where things were 'bottled up'. Both are simply ways of trying to cope with those things that aren't really cope-able with.

Some years on, the book published, I can reflect back and let other things surface. Such as – I really regret not having been there when Irene died, and this regret will not go away. I will have to live with it, made worse by the fact that it was some kind of choice of mine. I was struggling with the pain of a mending broken ankle, just out of the pot; I had sat up with Irene for a few nights. I knew the end was near, and somehow I knew that this night would be the one. I had been told that people often die in the early hours of the morning, after midnight and also that they often somehow wait for their loved ones to leave, so that they could get on with the business of dying. I left because I wanted Irene to know that she too could go. Her state by then was agonising, pitiful, her thinness meaning her bones stuck into the mattress. She cannot have been comfortable, though she didn't appear to be in pain. I wish I'd stayed but I didn't. Also, somehow, Irene had taken control of the situation – as she so often did – and she had actually said goodbye. Despite the years of her dementia, the years of not knowing if she even knew me or not, something extraordinary happened, something I later wrote about to a woman I knew, a humanist funeral celebrant. So weak and near death, Irene turned to me, sought me out in the room with her eyes, and made sounds that seemed like a sentence, and a tear rolled out of one eye. She'd had no speech for years, yet in her way, she was speaking. She was telling me the last thing she wanted me to know. This friend wrote back: 'I am sure you didn't imagine it, all kinds of things happen when someone rallies their last strength, and it was obviously you she would turn to and communicate with. The phrase that came to my mind when I met with you both was that she turned to you like a flower to the sun. It doesn't have to be verbal. Such experiences are to be treasured.' But I still wish I'd been there to hold her hand when she died. Instead, I had the inevitable phone call at one o'clock in the morning.

What's the legacy, apart from a fragile heart? I know that just when you think you're up and running again, grief trips you up, that it has qualities a little like water, that you can't really grasp hold of it, that it has a surprising power – and that it's essential. Loss is the flipside of love; true love can only lead to deep loss. But I don't want to make a career of loss, even though I know that becoming a professional mourner could solve the problem of how to actually *live*. Becoming a modern-day Miss Haversham means you don't really have to think about how to solve the meaning of life; you can simply remain stuck – problem solved. But being stuck isn't seen as healthy in another of today's prescriptions for healthy grieving – the idea of 'moving on'. Staying grief stricken for too long is as frowned upon today as it was in the nineteenth century, when the public began to feel that Queen Victoria really ought to discard her black wardrobe and 'live again'. We now know that her children hid evidence of her relationship as 'Mrs Brown' and I worked it out myself a long time ago that what you miss when you lose the love of your life is not just the person, but the relationship – and that another relationship can go some way to making you find glimpses of happiness again. One legacy of a long and happy relationship is that you understand how to create one, and I would love for it to happen again. I know that filling your life with activities and possessions is simply that – filling your life. Love really is what makes the world go round, plus knowing that you matter deeply and profoundly to another, that you are needed, that you have shared memories. We grieve for all these things too.

Following a class act is hard though, not only for me but also for whoever I did happen to have a new relationship with. She of course would have inevitable baggage too, carrying her own losses, and it would never be possible to have a long shared history with someone you meet in your sixties. I have seen it happen though – a late romance, someone to share the last chapter of your life with. Irene would approve. ■



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