

Struggling to stay on the straight and narrow

by [Sarah Meyrick](#)

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When Rebecca de Saintonge's husband was diagnosed with a terminal degenerative illness, it rocked her faith in unexpected ways. **Sarah Meyrick** talked to her



Looking forward: Rebecca de Saintonge

19th JUNE. So now, my love, I know the worst. Your brain is shrinking inside your skull. You are going to disintegrate very slowly, mind and body. You will feel our loving in rags and your God absent and I will hold you to my breast and cradle the shell of your skull, for you will have gone, my lover, my dear one. But not quite. But I am with you. I am your wife. We will see this illness as a journey we take together.

SO WROTE Rebecca de Saintonge in her journal, after her husband had been diagnosed with dementia with Lewy bodies (DLB), an incurable degenerative brain disease.

Jack, an Anglican priest, had been ill for some years when the devastating diagnosis was finally made. Although widespread, DLB is frequently misdiagnosed. It is a cruel condition: patients can fluctuate between lucidity and confusion, even from hour to hour.

They suffer visual hallucinations, systematised delusions, and spontaneous Parkinsonian symptoms such as slowness of movement, stiffness, and tremor. The disease affects language and the ability to reason. There is no cure.

Twenty years later, his widow has written a beautiful and searing memoir of their life together as they did battle with his deteriorating condition. He died after ten years at the age of 73 (she was 51).

Rebecca's agony, her exhaustion and isolation, as she witnessed the suffering of her beloved husband while struggling to look after him, is not, in itself, unique.

Her plight will be sadly familiar to all too many carers. ("Carer" is a term she can't bear. "I am not his carer," she writes. "I am his wife, his 'helpmeet'. And he is my lover.")

But where Rebecca's story parts company with most is that the way she kept her sanity was by taking a lover.

She never set out to be unfaithful: Nick was someone she met at a meeting to discuss a bonfire party. At the time, he struck her as unprepossessing, "rather small and brown". None the less, a chance encounter blossomed into an affair.

Unsurprisingly, it is this aspect of her story that has grabbed the headlines, leading to a recent appearance on daytime television (*Lorraine*, on ITV). "The experience has been a rollercoaster," she said earlier this month. "The interest has taken me and my publisher by surprise.

"I've had people hugging me in the street, saying: 'You echo an experience in my own family.' Someone else has just said to me, 'You don't know this, but my father nursed my mother through dementia, and he's never recovered.'"

It has not gone down so well with Jack's family (it was a second marriage for them both). "His children weren't happy, and I can totally understand that. My hope and prayer is that, when they read the book, they'll understand."

One of her greatest fears was that the book might belittle Jack. On the contrary, *One Yellow Door* exudes love for him, painting a picture of an extraordinarily happy and close marriage.

She met him while her first marriage was in its death throes, at a workshop he was leading on prayer. "His vitality was electric," she recalls. "He seemed to burn up the atmosphere, sparking it with laughter and throwing out, so apparently casually, the most astonishing possibilities as he talked in terms I had never heard before about a God I didn't recognise.

"He made it seem possible that this God was both real, and approachable — and, more than that, exciting."

That first evening, she "recognised" him. "Some might call it falling in love, but it wasn't quite that. It was simply — recognition. We were part of the same whole."

She adored him. "It's funny, but when I think of Jack now, I always think of colours. You know that blue of a high winter sky? Not vivid, but clear. Those were his eyes. His hair was thick and prematurely white, and his voice, his voice was moss green, the gentle, melting voice of a Welsh tenor. . . .

"But, in the same way that you can't describe a colour without reducing it to something less than it is, so you can't describe the complex, loving, innocent, passionate man who, while still struggling to get over the early death of his wife, walked into my own very broken life and gathered me up into this great bundle of laughter and energy and dedication.

"He was 51 — 20 years my senior — but I still had to run to catch up with him."

There followed, eventually, marriage (at the time they first met, he couldn't, as a clergyman, marry a divorcee), and a great deal of joy, she says. For some years, they lived in Zimbabwe, but

eventually it was clear that Jack was not himself, and they returned to the UK to seek medical advice.

MUCH of the book is based on the journal that Rebecca kept at the time. She details his deterioration, her desperation, and her emerging relationship with Nick.

At first, she was extremely wary of Nick. "Looking back over my journal, I can see he was quite predatory," she says now. She certainly did not move into an adulterous relationship lightly: she resisted his advances for several months.

There's a powerful passage where she visits very old friends. She wrote beforehand, explaining her situation, and asking them whether there was any way Nick could be God's gift to her.

"It was devastating," she recalls. "I told them honestly about Jack, and what was happening in my life, and that I had dared to hope that Nick was permissible, as he gave me the courage to go on living, and, more importantly, to go on giving to and loving Jack.

"Nothing could have prepared me for their response. . . . They accused me of being a Nazi, wanting to exterminate someone who had become inconvenient to me, to push the disabled out of sight."

Rebecca drove home in tears, shattered. The next day, the wife phoned. "As she was talking, I was barely listening, but I was suddenly aware of what I can only describe as Christ's presence. It was tangible. I felt as if he was literally putting his arms around me, and making a barrier between her voice and my being.

"To the day I die, I will never forget that moment. My instant thought about it was not that Christ was condoning my relationship with Nicholas, or forbidding my relationship with Nicholas, but just that he was with me. Simply that.

"In my circumstances, Christ was with me. There was no judgement, just his presence. He was holding me."

THE relationship with Nick ended six months after Jack's death, "quietly, gently". She is not ashamed of what happened, she says, although she is committed to fidelity. She believes that she and Nick — who had a profoundly disabled child — gave each other "a window in the darkness, a moment of light". She has had no further contact with him.

It took her five years to write the book, and she finished it six years ago, never expecting it to be published. It was rejected by agents. "But I thought I'd give it one more go," she says.

She wrote it for two reasons. "I wanted people who had been in the same position to have a voice. I talked to other women who had taken the same route, and no one understands.

"Secondly, I felt I'd learned so much, spiritually. My theology had changed. Everything had changed about my understanding and my relationship with the divine. And I could only write that story against the backdrop of what had happened."

IT IS, then, a book as much about one woman's spiritual journey as it is about the experience of Jack's illness and her affair. After his death, she spent ten years in a spiritual wilderness, mourning the loss of her faith.

"There is no doubt that while the presence of the suffering Christ became increasingly real to me as our own suffering deepened, my concept of God grew darker and dimmer," she writes. "So it slowly dawned on me that what I had lost was not my belief in a spiritual reality, but my belief in the theology we had been brought up with.

"What I had to face was not that there was no God, but that the concept of God I had previously held, and my understanding of how God interacted with the world and with humankind, had been a distortion. I realised I had to unlearn everything and start all over again."

Over time — "a long and lonely process of shedding [her] skin" — she found her way to a new spirituality, taking great comfort in the work of writers such as Richard Rohr and Marcus Borg. "I realised that what I struggle with, other people had, too. I was not being subversive – it was part of a new way of looking at things."

Ten years ago, she married a musician, Robin, "and he's wonderful". She has lost sleep over the book, but feels that it has given her a voice to discuss the spiritual issues she feels so passionately about.

These days, she is a Quaker. "It's that whole business of wanting to worship without words. When I joined the Quakers, I felt I'd come home."

Sarah Meyrick is Director of Communications for the diocese of Oxford.

One Yellow Door: a memoir of love and loss, faith and infidelity by Rebecca de Saintonge is published by DLT at £8.99 ([CT Bookshop £8.09](#)).

Since this interview was conducted, family members of the man named here as "Jack" have contacted the Editor independently to express their unhappiness about the book. They say that they were not consulted nor shown a copy of the text; also, that the author, by using her own name, has not sufficiently protected the identity of their father. One has written: "We would have wished this sorry tale had remained a private, family matter."