

PHILIP INGRAM

Partners in Care

Sharing

INTRODUCTORY NOTE

My wife, Pauline, died from Alzheimer's disease at the age of 59. She was 51 when diagnosed after several years of problems. I cared for her at home. For the first 3 years, I maintained my employment, albeit on an increasingly part-time basis, but resigned from work and cared for her full-time for 5 years when her needs demanded round-the-clock attention. She remained in her own home to within 5 weeks of her death,

when fracturing my leg put paid to my direct caring role.

The article was originally written along with two or three others as a result of a commission from Suffolk Carers for their magazine. This was some time before Pauline's death. In 'Sharing', I tried to encapsulate the story of our marriage and the effect that Alzheimer's disease had had on that relationship. However, the writing took over from the concept and it became too much of a personal

statement about us for me to be happy about it being read by others while Pauline was still alive but unable to contribute, so I didn't offer it for publication but filed it away. I think the writing was, in any case, a sort of much-needed therapy for me at that time.

Philip Ingram
July 2003

We have been married for 34 years. Pauline and Philip. Two P's in a pod. We thought of naming our house 'The Pod' but never got round to it.

A good marriage, but we had our difficulties among countless joys. We had many shared pleasures – the things we enjoyed together – the theatre, music, walking, gardening, village life, but we also had personal interests that we jealously guarded as 'mine', wanting and receiving the encouragement of our partner, but not their participation.

We were always in total unanimity over the upbringing of our only child. Pauline bore the brunt, but we shared where possible. And we worried together, oh how we worried, over those few fraught teenage years – but we came through them largely unscathed and so, surprisingly, did Catherine. We shared a mighty pride in her.

We formed and maintained individual friendships over the years, but have more that we savoured jointly. We've shared much sadness – family bereavements, friends too. Occasionally we had concerns over each other's health. Pauline's hysterectomy worried us both until, after the operation, the surgeon said that all was well.

We had worries over work too, particularly when I was made redundant. Out of work for 6 months. The sharing continued, just the balance changed. Pauline became the main breadwinner while I gained a closer acquaintanceship with the Hoover, washing machine and cooker. Unknowingly, my temporary role reversal became a rehearsal for things to come.

My redundancy coincided with Catherine leaving home to start her own career. Time for reflection and reappraisal. We talked about 'us', what was important and how to spend the rest of our lives. We were free and made our plans. The whole world was ours.

But then something came between us. I didn't know what. The sharing became more difficult, Pauline, stran-

gely less responsive, not so interested in home, or me, or 'us'. Nothing I could really identify yet we were not together in the same easy, effortless way. Why? What was it?

Whatever it was was quiet, slow and insidious. It took 3 or 4 years to show itself with more obvious signs of unusual behaviour, the signals of the bigger but hidden problems that lay ahead. They occasionally broke through the surface and rose momentarily above the restless sea on which we had been sailing during those unsettled years. We were not good sailors. Even then, the peculiar uncharacteristic things Pauline said, did or didn't do from time to time, formed no discernible pattern until about 2 years before diagnosis. Then some of the problems she had been keeping to herself became apparent to me. I could see that she had lost confidence, was having real difficulties, not with me or 'us', but with herself and she needed help. We began to share again.

But sharing is difficult when you don't know in what you are sharing – when the basic nature of the problem (still undiagnosed) made it increasingly difficult for Pauline to put her thoughts and concerns together in any logical form, let alone articulate them. Although she hid a lot from me, I increasingly experienced the effects of her difficulties and thus was able to share in some of the traumas that beset her and the frustrations she endured, although I didn't really understand what was happening to her.

I instinctively felt, and then became certain, that it was something more than the 'mild neurosis' her doctor had identified. However it took those 2 years of problems, problems that occurred more frequently, became more extreme and quite bizarre in character before tests eventually led to diagnosis and I learned what we had to face. The sharing then became easier. It also became more demanding.

It became easier because there was a great need to share, in both practical and emotional terms. Pauline



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became more dependent. We shared not only more household tasks but Pauline shared my perception of things when the familiar became confusing to her, my calmness when she became agitated, my memory when hers let her down. I shared her determination not to let this 'thing' defeat her; she knowing it was destroying her brain, her very essence, but courageously getting on with life, in spite of it all. In the sharing we both gave each other a strength that individually we may not have been able to find, let alone utilise.

Sharing became more demanding in that it became the most physically exhausting, mentally draining and emotionally wrenching period in the whole of our life together. It is now 7 years since diagnosis. It has been the most awful time of our lives, but also the time of greatest togetherness and, to me, the most fulfilling. We shared the same tortuous journey. We both know very intimately what hell is like – every horrifying, violent and disgusting corner. A vile place without rest or peace. We experienced it together, and survived it together; we both, fortunately, came back. Mercifully, Pauline no longer remembers. She is calm now. At peace with herself. She cannot speak. She can only stagger a few

paces when supported. She knows not the day, nor cares. She is bathed, she is fed, she is warm, she is loved. And she gives love, to me. She warms me. She fills me, feeds me with all that was, as well as with all that is. The sharing continues. Her frame frail, her brain all but destroyed and to most friends, the old Pauline has gone, is no more. They see the shell. Almost a human vegetable, but not quite – as yet. This is what Pauline has become. This is what she is today. But what she is today is composed of all that she was, all her yesterdays, all that life shared with me and mine shared with her. It's still there. Strong. Stronger. It hasn't gone. Together we have beaten that wretched Alzheimer's disease. I know it will take her life, perhaps soon, maybe a long way hence. And when it does, it will be the disease that has been destroyed, not us.

Declaration of interest

None.

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