

## **"I fall in love with her all over again."**

When our loved ones become ill, the task of caring for them often falls on the people who love them most. Their sons and daughters, their husbands and wives. But caring for the love of your life can sometimes be the most challenging and demanding of tasks. And yet, as Robert Ferguson so movingly describes, love somehow has a wonderful way of enduring.

When Robert's wife Olive was diagnosed with dementia he became her full-time carer. It was a role he took on willingly and proudly. Because Robert had been devoted to Olive ever since the day they first met, over 60 years ago.

*"Our first date was to a fish and chip shop for an orange drink and a chip. How romantic was that?", Robert laughs.*

But love soon blossomed and four years after that first date, Robert and Olive began their journey as a married couple. A journey that brought them immense joy, occasional sorrow and three wonderful children. Two sons and a daughter. But what made the journey so special was the fact that they took it together.

Then Olive became ill.

*"Her attention started to wander. On one occasion I was a patient in hospital. She visited me and as I was talking to her, I noticed that she wasn't looking directly at me. She just kept looking either side of me."*

Once Olive was diagnosed with vascular dementia Robert dedicated himself to caring for her and making her life as rich as possible.

*"Sometimes I think she was aware of what was happening. Quite early on she asked me to write the names of our two sons on the back of their photographs so she could remember them."*

A few months ago, Robert wrote and spoke about his experience as a carer on Radio Ulster's Thought For The Day. His account is candid, insightful and deeply moving.

*"You are there 24 hours a day. You cannot walk away from it or leave it. Privately provided carers or helpers from the NHS may visit but that's only for a few hours. That still leaves up to 20 hours in the day when the responsibility is yours. Daylight hours in the warmer months aren't too bad. It is wonderful to see your loved one getting out of the wheelchair and using it as a support to enjoy a few minutes walk. Evening and nighttime hours are more difficult. No one can prepare you for being woken at 3 or 4 am to take care of a toileting mishap. You just have to cope with it and do your best."*

Robert's account also captures the profound effect caring can have on a relationship. And it does so with heartbreaking honesty.

*"These are the times when the marriage vows become meaningful. These are the times when patience is stretched to the limit. These are the times when extreme frustration on the part of the sufferer and carer are expressed not only in words but sometimes in actions. These are the times when your faith and good nature are really put to the test and you wonder what lies in the future."*

Sadly, what that future held for Olive was a steady decline. In the space of a few short years she became more frail and more prone to infection, until finally, she was admitted to hospital. But although Olive got the best of care in hospital, Robert was at times excluded and ignored.

*"I think there's a problem with the way information is given to families. I realise the staff can be busy but I sometimes found great difficulty making contact with the consultant who was looking after Olive. And when I did meet her, it was in a ward being used as a furniture store. She talked about Olive's care pathway but it wasn't written down. I later had to rely on my own scribbled notes."*

Poor communication between medical staff and families can often add to their stress and confusion and, especially at times when emotions are so raw and hearts so vulnerable. Not long after Olive passed away, a nurse asked Robert to wait outside the room while the doctor examined her.

*"He was a sombre individual. I hadn't seen him before. I waited outside. And when he came out, he didn't look in my direction. He just ignored me and walked away down the ward. I said to myself. I've just lost my wife. Could you not just offer sympathy? Or even look at me?"*

Central to the whole idea of palliative and hospice care is the understanding that the needs of a patient's family, and in particular, their loving carers, are of vital importance. It is a subject Robert is passionate about.

*"With palliative care the needs of spouses and families must be viewed as an integral part of the whole. Ideally a consultant or senior member of the team should provide information about a patient at regular intervals, in a comfortable environment with every effort being made to make the relative feel relaxed. Written summaries of progress, treatment plans and outcomes should be provided."*

Indeed Robert feels so passionately about the importance of proper palliative care that he now serves in a voluntary capacity on an NHS palliative care user involvement forum and with various charities concerned with caring for older people.

It's almost as if Robert's darling wife Olive left him a very special gift in a busy and fulfilled life pursuing his great passion for the care of others. His days are, in part, taken up with meetings, forums, conferences and visits to dementia sufferers in their own homes.

*"The number of people I have met, the experiences I have had. It's been fabulous."*

But Robert still finds time for his hobby of photography and the dutiful care of his home and garden. At all times he keeps with him the memory of his darling wife Olive.

*"I miss her every day. She had the most beautiful voice. I have a recording of her. It's very faint. But every time I listen to it, I fall in love with her all over again."*