

MARK SEYMOUR'S INTERVIEW

Title: Living with Alzheimer: A harmonica for Ronnie

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- **Before Alzheimer was diagnosed, have you ever noticed something wrong with your father's health?**

Mum was the first to notice something wasn't right with dad. Only little things to begin with but mum could see the changes. Dad had always known for his slightly cheeky sense of humour, so when mum would mention it, we would just laugh it off and say 'it just dad being dad'. But it became more noticeable that dad was starting to develop some obsessive behaviours and not responding in the way would expect him to. He started to fall asleep at the table and fall off his chair. The obvious signs like forgetting things and repeating himself. Eventually mum convinced us that there was something wrong and that when we had to persuade dad to see the doctor and go for tests.

- **Once the disease was identified, how did you and your family react? Were you, your mother and your father, aware about what it could be meant?**

Dad and mum were aware that the condition ran in his the family as they had watched his mum gradually loose her fight with dementia in a home. Before the diagnosis Dad had read about the illness and possible ways of avoiding developing dementia, he tried all he could to postpone its grip, he kept fit, ate foods that were recommended, and kept his mind active. I don't think any of us were really prepared for what was going to happen though. You can read the facts but it's completely different when it someone you love and watching them slowly lose their connection with you and withdraw into the safety of their past memories. Of course it was hardest for mum, Ronnie was our dad and her husband, but he was so much more, she was losing her soul mate, her partner, her best friend and lover.

- **Did you decide in those very moments to take pictures of your dad? And why did you take that decision?**

It was not a conscious decision to record dad and his dementia, taking photos of mum and dad was just something I always have done and I just kept on doing. It wasn't until I was looking back at some of the photographs that the importance of these pictures really resonated with me. Suddenly the truth of the illness was there in front of me, the changes so clearly recorded, and I knew that however hard it was I needed to keep taking his photographs and make sure I told dad's story right to the end.

- **As I told you in my mail, several years ago, when I was a volunteer, I had been taking care of an old man afflicted with Alzheimer for a few hours a day. He didn't remember anything about the present, but he had some vague memories of his youth. Every day was as he met me for the first time. Was the same thing for your dad?**

It was hard when dad would talk to you thinking you were someone else, or worse not acknowledge you at all. Sometimes he would talk about people long gone from his life and even talk as if they were actually there. Very early on we realized if we challenged him or tried to

explain he was wrong it would lead to him becoming very distressed and not understanding, so we learnt to play along. He was generally happy in those memories surrounded by the people he loved when he was a young man, so why would we want to upset him with the truth, the truth was only reality to use, not him. Dad had so many wonderful memories so we tried to help keep those alive by taking him and mum to places they used to visit before it became too difficult to take him out and then by bringing him old photographs when he was in the home, like his old Vincent motorbike.

- **What did you and your mum feel when your father started not to recognize you no more?**

Mum was in denial, she would self-comfort by trying to find the positive each time we visited saying 'don't you think he was better today', 'he was talking to you', 'he knew exactly who you were', 'he asked after you', and just like with not upsetting dad it was important not to question this with mum as she was finding it so hard to deal with, so we would just say 'he was pleased to see you mum' and leave it at that. Mum was desperate to keep Ronnie alive in all our memories as the man he was, and she genuinely could not see him deteriorating, she just saw Ronnie, the man she had loved since she was a young girl.

- **How did you organize your photographic project? That is, it is an emotional, deep and agonizing project. I believe that working with, looking over and over at, publishing, explaining those pictures, has been a hard proof of courage as a son and as a reporter.**

As I said, taking the photographs was completely natural to me, I always have my camera to hand. The difficulty came sitting alone in my office and editing the photographs, that was when it confronted me, on my screen, there was no shying away from the reality of the what dementia was doing to my dad. That was the time that I would have my private thoughts and tears, as I needed to be strong for mum.

- **Which was the most difficult moment to face with this matter?**

We had suspected for about six months that dad was becoming too much for mum to manage. We tried to put support in place to enable her to keep him at home but it just did not work out. Dad's behaviour was becoming more challenging and although mum never said anything we knew she was getting scared and we needed to do something for her safety and health. It was a long process in getting mum to consider even respite care and as it happened a family event meant that an opportunity to try a short break at a local care home arose. We couldn't explain to dad where he was going so we had to pretend it was any other day and persuade him to get up and dressed and leave the house for a coffee. In reality we were taking him to the home. As it turned out, dad would not come back home again, as we had to make the decision for him to stay permanently. The photographs of mum as she is comforted by the staff break my heart. She blamed herself for leaving him, she was so desperate to keep him with her and care for him, even though it was not possible at that stage. When mum walked back out the door it was the first time in their married life that they had ever spent a night apart, and it is all there in her eyes.

- **Alzheimer is one of the most current diseases in the world. Which suggestions would you recommend to the families affected by it?**

Everyone finds their own way of dealing with it, but I think you need to be honest and talk about the situation. There is a lot of information out there and it is important that you understand what is happening, how to support the person and know where to get help when you

need it. Finding strength from each other is key, whether that's within your family and friends, or from carers and organisations. Getting the information out there and raising awareness is what I am aiming to do with dad's story and photographs.

- **Which memory will you have of your dad?**

Dad was an inspirational role model in my life, as a husband to my mum, a father to me and my brother and a grandfather to his six grandchildren. He was known for his handy man skills not only around the house where mum still lives surrounded by his hard work; the perfectly fitted cupboards, the handmade bricks for the garden wall he built himself, but also the more quirky side to his creations like his very own roller-skates so that he could go out with the kids when they got there's and the canoe which he would walk down to the river tied to his bicycle! But the image that makes me smile is captured in a number of photographs I've taken of dad over the years, and that's him playing his harmonica. And so the title for my work seemed so apt, Living with Alzheimer's: A harmonica for Ronnie.