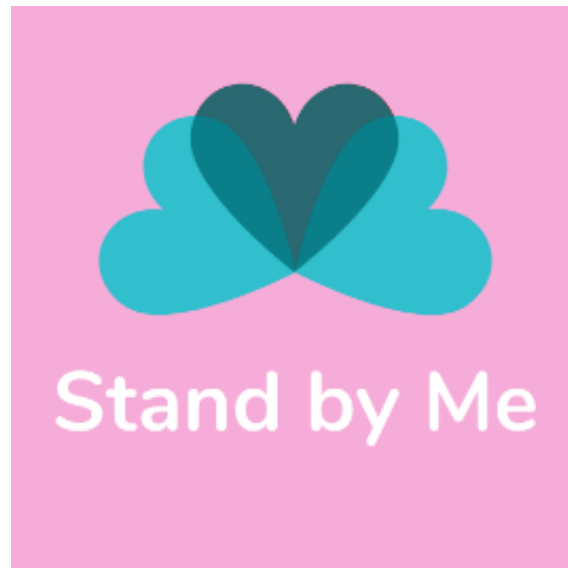


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Story 1: Jimmy and Ann

This is one of eight anonymised stories of couples with a learning disability after one of the partners received a diagnosis of dementia. Each story is available to read or download and listen to [here](#). The stories include both happy and sad events. You may wish to read, or listen, with someone you can talk to about dementia.

Stand by Me is a collaborative research project between University of Stirling, University of Edinburgh, Key and Community Lifestyles and Alzheimer Scotland. This research was supported by Dunhill Medical Trust.

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Jimmy and Ann

Jimmy and Ann met in Scotland in the 1990s.

They were both living in a community that supports people with a learning disability.

At the time they lived in separate houses, but close to each other.

“They just started as friends, which developed into a relationship.” (Ann’s sister)

Jimmy and Ann were a good match. They got the support they needed to enjoy their relationship.

“Well, I thought she was a nice lassie. Then we went together. And I didn’t want to go too quick. Then I said to her, what do you think of getting engaged? She said, ‘aye’. So, we had an engagement party.”
(Jimmy)

Jimmy and Ann got engaged in 1998.

When Jimmy and Ann got engaged their families thought they should have a long engagement but that’s not what Jimmy and Ann wanted.

“They went and saw the minister and I think they were married within a year, that was May 1999.” (Ann’s sister)

Jimmy and Ann’s families were supportive of the relationship but were not sure about their idea to get married. They were worried the marriage might not last.

“Well, I don’t think my uncle liked the idea.” (Jimmy)

“They wanted them to live together for six months, and if it worked, then they could get married, but that’s not what Jimmy and Ann wanted because for them it was important to be married if they were living together. When I thought about it, I realised that everyone else is given a right to fail, why should you not have that right, just because you have a learning disability?” (Ann’s sister)

Jimmy and Ann had several meetings with their families, support workers and social workers.

In the end everyone agreed with Ann and Jimmy that they should be able to get married if that’s what they wanted to do.

Jimmy and Ann wanted a big wedding.

“My dad had thought it would be a small wedding, that eight of us would go to a registry office for the ceremony, then on for lunch but that wasn’t what Ann wanted.” (Ann’s sister)

They got married at a local church. The minister waived her fee, the church community decorated the church with flowers and the minister’s neighbour chauffeured them in his silver Mercedes. A friend made a wedding dress for Ann.

“Oh, there was quite a lot of folk there. Friends and family, a big thing.” (Jimmy)

“The church was absolutely ¹stowed, full to the brim, and it was a lovely wedding ceremony. Ann had picked her favourite hymns Make Me a Channel of your Peace and Give Me Joy in My Heart (Sing Hosanna) and members of both families participated in the service.” (Ann’s sister)

On the day the best man forgot the rings.

“So, Ann had to wear [the minister’s] ring as a symbol, and I had to wear the best man’s ring.” (Jimmy)

Jimmy and Ann moved into their own flat.

They continued to be supported by workers from the community.

¹ Scottish term meaning a lot of people present

“We got support every day, they came, helped us cook dinner, made a menu plan up for shopping. Then we’d go to Tesco and buy the stuff.”

(Jimmy)

Jimmy and Ann both worked during the week and shared household tasks.

“Well Ann worked at Morrisons. I was working in the nursing home. Cut the grass. So, I was working there, cutting grass and all that, doing things.” (Jimmy)

They were very sociable and enjoyed going to clubs, the theatre and cinema and taking trips. They helped each other.

“For the first few years they just had a very happy life. The way the relationship worked was Ann could read and write, so she organised the money, and she would manage everything at home. Jimmy was more worldly, so he would organise for them to go on trips like on the Waverley, to shows or the cinema and they always went on their annual holiday to Butlins for a week.” (Ann’s sister)

Around ten years after they met, people noticed changes in Ann. She seemed less confident, and Jimmy started helping her with things that she had usually done herself.

“She became anxious doing things that she’d always been very good at. She was less sure of herself.” (Ann’s sister)

Ann went to see a psychologist, whom she had visited a few years before. The psychologist also felt that Ann had changed. She started to see Ann more often during the next years and in 2011 Ann was told that she had dementia. Ann’s sister, the psychologist and her support worker were with her on the day.

“I started to cry, and she got up and she put her arms round me and said: ‘Don’t cry, because if you cry, I’ll cry’. That became a wee bit of a mantra for us, because as the Alzheimer’s developed sometimes Ann would cry and we just used to always say ‘If you cry, I’ll cry’ and she always stopped.” (Ann’s sister)

The psychologist and support workers talked to Jimmy about Ann’s dementia.

“I just needed advice, to say what happened, what’s going to happen. And they showed me a bit of paper with wee triangles, what would happen and all that. And I’d understand what it was about.” (Jimmy)

Over the next years Ann started to need more support. Jimmy and Ann moved into a new flat and Jimmy did more things at home like hoovering or ironing.

Because of her dementia Ann sometimes had seizures and Jimmy made sure she would get help.

“When she took a seizure, you felt it coming. Then I had to ‘phone for the doctor, the doctor had to give her an injection”. (Jimmy)

Sometimes to give Jimmy respite, Ann’s sister would take her to a spa for the day and a support worker would arrange a day out for Jimmy. One day they went to The Titanic Museum in Belfast which Jimmy wanted to visit.

Many things stayed the same. Ann and Jimmy continued to visit her sisters and they all continued to go on holidays together, including a trip to America. Ann also continued to work at Morrisons, although she worked less hours.

“This is like therapy for Ann, and the Morrisons Manager said as long as she wants to work and she’s capable of coming in to work, we will support her to do so.” (Ann’s sister)

Jimmy and Ann had support from Ann’s sisters, workers at the learning disability service and health professionals at the hospital.

On a few occasions Ann had to go into hospital. Sometimes her sister went into the hospital and stayed with her; sometimes her support workers sat with her during the day.

“We made sure Ann was well looked after.” (Ann’s sister)

Jimmy felt that it helped him to talk to workers when things were difficult, and they took time to talk to him about dementia when he had questions.

“The support saying, Jimmy, she can’t help it when she’s saying that. She still loves you. [That was helpful].” (Jimmy)

A service manager at the learning disability service arranged for Anne’s sister and Jimmy to attend their staff training events about dementia to understand how it develops and the support Ann would need in the future.

After some years Ann was feeling more poorly and she needed more help. She moved to a special house within the community where Ann and Jimmy had met. The house had wider corridors for wheelchairs and there were more staff to support Ann. People asked Jimmy and he agreed that it was the best place for Ann.

“That place there, they’ve got the equipment. And the staff are awful nice in there as well. [The manager] said, you can come up and see her anytime. I went up every day, had my dinner and tea up there.” (Jimmy)

Jimmy visited Ann every day. When Ann found it more difficult to speak Jimmy and Ann would sit together to hold hands and listen to music. The manager of the house made a playlist for them with their favourite songs.

“Songs that were played at their wedding, songs that they liked to sing together, songs that they danced to. I set up the headphones for Ann and then gave Jimmy his, and I switched it on, and it was one of those moments that kind of will stay with me for life. Because as soon as I put the music on, they were like in a bubble, and she was gazing at him, and the two of them were smiling at each other, and they were singing along to the songs.” (Service manager)

In 2017, Ann died. This was a sad day for Jimmy. It helped him to see how many people came to the funeral to celebrate Ann’s life.

“[People] queued all the way around the cemetery waiting to get in - there was hundreds of people there, it was incredible.” (Ann’s sister)

“They all wanted to come and pay their respects. I think it was lovely to know how much she was loved.” (Service Manager)

Jimmy is still in regular contact with Ann's sisters, and he often visits Ann's grave.

"I'll get some flowers for Valentine's Day then I'll go up. Sometimes I talk to the grave, so I do." (Jimmy)

Jimmy enjoys going to college to learn new skills, he enjoys going swimming, socialising with friends and is part of different local activity groups. He likes to look at photos of Ann and their wedding and holidays together. He often thinks of Ann and treasures his memories of their time together.