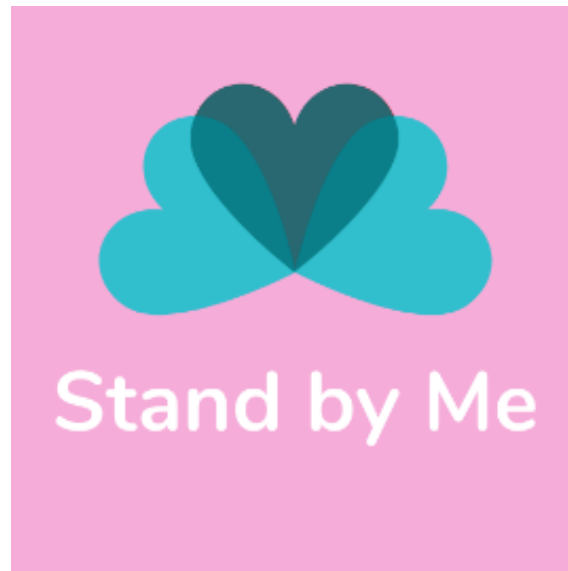


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## Story 4: William and Janet

*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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## William and Janet

William and Janet live in a small town in Scotland. They have known each other for many years and have always been part of the same group of friends.

*“There was an older client group with disabilities. They frequented the same places, the same clubs. Janet was always with him.”* (Care Manager)

At first, they were in relationships with other people. When both their partners died, William and Janet continued to spend a lot of time together and their friendship turned into romance. That was about five years ago.

William and Janet have an age gap of almost 20 years. William is in his 70s and Janet is in her early 90s. This means that Janet is not as mobile and William used to walk to her house to visit her. William used to live in a block of flats that was quite run-down, but then he moved to a new property that was closer to Janet and they were able to see each other more often.

He often spent the evenings at Janet’s house.

*“William and Janet continued their friendship and then it just developed. But they have known each other for years.”* (Janet’s Key worker)

*“It wasn’t until the housing association made the decision that they were going to demolish these properties that we managed to get William to move. He is within walking distance of Janet’s. That was it, the relationship just grew from there.”* (William’s Care manager)

William and Janet were supported by two different services and lived in their own flats. Both services worked together to support the relationship.

*“The support staff would facilitate them going out for dinner and spending time together, going to social clubs. When William went there, supper was left for them, so Janet could make cups of tea and their sandwiches were ready.”* (Care manager)

Then William and Janet got engaged just as the COVID-19 pandemic started.

*“He bought her a ring and she bought him a ring and that is it.”* (Care manager)

*“They didn’t have a party or anything, because then we were in lockdown.”* (Key worker)

Around the same time as William and Janet became a couple, people noticed changes in William. He started forgetting his keys and the names of people.

*“I never ever knew him to have any problems with locking himself out or not finding the keys, and then all of a sudden this was a biggie.”* (Care Manager)

William went to see a psychiatrist and he was diagnosed with dementia.

Staff talked to Janet about William’s dementia. They explained to her that his brain was not working as well anymore. Janet noticed that William was repeating himself more often.

*“But it didn’t upset her. She just noticed that he was repeating himself.”* (Key worker)

Staff think that Janet had a better understanding of what dementia means than William. Looking back his care manager wonders if they could have been better in talking to him about it.

*“I don’t even think he was aware of the condition, never mind trying to explain what it would be like and how he was going to be.”* (Care manager)

Janet and William saw each other often.

Before the Covid pandemic they would go together into town, go to cafes and different social groups.

*“There was a club they used to go to twice a week, a Monday and Thursday.”* (Care manager)

They also enjoyed spending time at Janet’s house, watching TV together. They would drink tea and they would have a chat.

*“Saturdays, they did Saturdays. They would go out and they would maybe go to Morrisons or one of the wee café bars in the town and they would have their lunch and then back up to Janet’s. A lot of the time it was just being in each other’s company. They seemed to really have a good...they seemed to have fun together.”* (Key worker)

Then COVID happened and people were asked to stay at home and not visit other people. Janet was upset that she could not see William.

*“She was devastated. But at the time nobody could go anywhere. She would cry and I am like ‘I know, I know’.”* (Key worker)

William's staff were worried how he would cope with the lockdown. He had always been very independent and liked being out in town. But William did not mind spending time in his flat. His care manager wonders if he started to enjoy spending more time at home because of his dementia.

*“Previously we couldn't keep tabs on William. He was such a free spirit. Lockdown completely changed him. He coped brilliantly with it.”* (Care manager)

Then Janet had a bad fall and needed to go to hospital for a few months. This was a confusing time for both. When restrictions eased, William would start to walk to Janet's house, but she was not home.

Because of COVID, William could not visit Janet in hospital, which was difficult for her.

*“She always asked about him. Always, always, always.”* (Key worker)

Before dementia, William did not get a lot of support. He preferred spending his days by himself, out and about. Sometimes his care manager was worried that he was not looking after himself well enough.

Since he has dementia, William is getting more support and he seems to accept and enjoy it more. He enjoys going fishing with support workers and likes his new flat.

Neither William or Janet have family who are regularly involved in their lives.

*“It was always just him. William and his group of friends, the people he associated with and that was a learning disability community.”* (Care manager)

After her fall, Janet stopped walking and needed more support. She moved into a care home for older people. The plan was for Janet to return to her flat when she was better but because she still finds it difficult to walk, it was decided that Janet should stay in the care home.

*“She went into the nursing home, she wouldn’t walk there either. And see, every time you would go up and visit, she would look really good. I think her life is good, apart from William if she could get him in.”* (Key worker)

At first it was confusing for William that Janet did not live in her flat anymore. He did not want to visit the care home. Staff explained to him that Janet now lived there.

Janet missed William and was anxious to see him again.

*“Janet was really fretting. She went downhill rapidly, wasn’t eating, really unwell.”* (Care manager)

Now William visits Janet in the care home once a week. Janet’s health has improved since then. Both enjoy spending time together.

*“Reports are that she is flourishing and William is really enjoying the time together. Janet just takes William as he is, always has done.”* (Care manager)

His care manager has asked William if he would like to move into the care home, but he prefers living in his own flat.

*“I would say, would you like to stay? ‘No, no, I like my own house’. He is not for moving.”* (Care manager)

Staff want to continue to support their relationship with regular visits. As COVID restrictions are easing William and Janet can hopefully start to meet again in town and do more activities outside the care home.



*“If things were getting back to normal, maybe you could meet out of the nursing home. You know, like meeting in the café that they used to go to. But they would need support.” (Key worker)*

William is active and is keeping well and his staff want to support him to live in his own flat and be independent for as long as possible.

*“He is really doing well. For the length of time he has had the diagnosis it is not as if he has deteriorated. I see a difference in him, but there is nothing causing me concern. I don’t think William is ready for a care home.” (Care manager)*