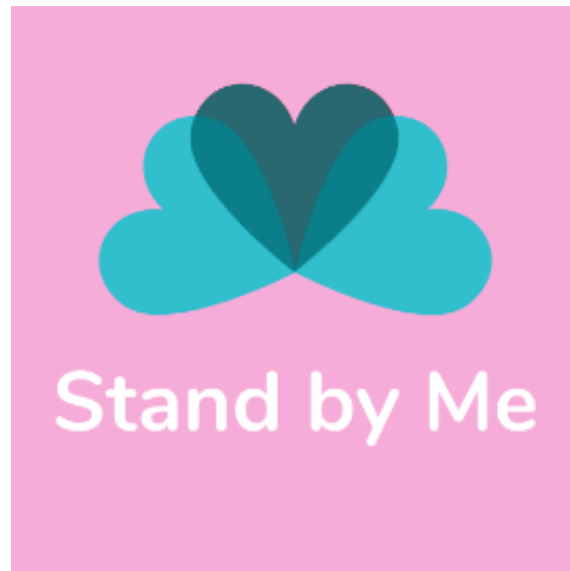


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## Story 6: Mary and Paul

*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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## Mary and Paul

Mary and Paul live in England. They have been married for over 20 years.

They met at work, where they were supported by the same service for people with a learning disability.

*“She met Paul probably about a year after she'd been at the service.”*

(Mary's sister)

Paul has been supported by the same service provider since he was a child. Mary moved into a house supported by the service in her early 30s, a few years before her mother died.

*“They are a couple that have been supported by our service for many, many years. They didn't live together, but they lived in the same area.”*

(Staff member)

Mary and Paul wanted to get married. Their families were surprised at first but were supportive.

*“It wasn't a hesitation about getting married, but it was more, we'd never thought she would. Going back that long ago, people didn't really expect anyone with Down's syndrome to marry. But no, there was nobody against*

*the wedding. People were thrilled for them, and it was a very happy day.”*  
(Mary’s sister)

The service also supported their decision.

*“Why would that not be something that they could do. I can’t stress enough that they were just a normal couple, a married couple that fell in love, and the service and both of their families supported them.”* (Staff member)

Mary and Paul got married in 1999.

They had their wedding in a church with family and friends.

Mary wore a white wedding dress and Paul wore a suit, and they had a horse-drawn cart at their wedding. Mary was very proud:

*“Me and my sister chose the wedding gown and the veil and the shoes.”*  
(Mary)

*“Our mother had died by then. We pulled all the stops out for her and then had a big reception. And as I say, everybody...if you look at the photos, you'll see lots of the residents, most of the residents are at the wedding in the church.”* (Mary’s sister)

It was a very special day for Paul and Mary and they often looked at photographs of their wedding day and like to remember it.

Mary moved in with Paul. For many years they had a very independent life together as a couple. Staff only came for a few hours a day to provide support them.

*“They did everything together, and they helped each other and were very close. They looked after each other and that was a big factor of their relationship.”* (Mary’s sister)

During the week they went to work. Mary worked in a café and some days they worked together in a bakery. They went on holidays together and often visited Mary’s sister.

*“They used to come to me, certainly every Christmas for a week, every Easter, every bank holiday, weekends, we'd go on holidays in between, we'd go out for the day, we did lots of stuff. There's loads of photos that I have of us all doing different things.”* (Mary’s sister)

Then, around seven years ago Paul noticed changes in Mary and told staff about his concerns.

*“He would say to staff when things that she might be doing were a little bit odd. You know one day she could get to work independently and then she would be late home and it became apparent that she had got lost. Paul would alert staff to say Mary is not home yet or she got on the wrong bus.”* (Staff member)

Staff also noticed that Mary was doing things that were not part of her usual routine such as packing unusual food for her lunch at work, or forgetting how to do certain tasks.

*“It helped that the staff team have quite a lot of awareness of dementia because they have supported other people that have lived with a diagnosis. So, they started probably picking up there is little changes that you then know in your gut instinct that is not right.”* (Staff member)

Staff started to document the changes they saw in Mary and discussed these with a health professional.

A doctor and staff members met with Mary and Paul to tell them that Mary had dementia. Staff explained that this meant that her brain was not working as well anymore.

They used pictures and social stories to talk about dementia with Mary and Paul, and they both started to attend a memory café for people with dementia and their families.

The café is a social place where people with a learning disability and dementia, their partners, friends and family can meet. People have and coffee and cake, there is often arts activities, games, singing and even animal therapy.

*“Mary would come supported by her staff, but Paul would come just for a hug. He would come in just for a cup of tea and a hug. But it was providing them both with something although in quite different ways.”*

(Staff member)

Later on, Mary found it difficult to talk about dementia, but Paul found it helpful to have someone to talk to.

Staff came more often to the house to support Mary and Paul.

They made changes to the flat to make life easier.

One member of staff met regularly with Mary and Paul to talk about what they wanted for the future, and how they were feeling.

*“Mary and Paul used to say to me all the time we want, as long as we can, we want to live as a married couple the way that was normal for them.”* (Staff member)

Then Mary started to sleep less and to get up during the night. Paul tried to support her, but it started to be difficult for him.

*“He was so tired because he was up all night. I think a lot was her wanting to have a bath at two or three in the morning, but she started to have slips and falls.”* (Staff member)

Staff felt that Mary needed more help and that it might be good for her to move into a house with more staff support. They talked to Paul and Mary about it.

Around three years ago Mary and Paul moved into a house with two other older people with a learning disability. Staff were there to support people day and night.

At first, Paul did not want to move out of the home he had lived in with Mary for 20 years, but he wanted to stay with her.

*“They wanted to stay together and that’s what we did, we kept them together.”* (Service manager)

*“It had more of an impact on Paul, but then Paul was isolated living in the bungalow. Mary is safe for now because she has got 24-hour care support and Paul has company when and where he chooses to have it.”*  
(Staff member)

It was difficult for Paul to now be in an environment where staff were present all of the time, and to see the changes in Mary.

He decided to move into a room by himself which helped him. He also started to see a counsellor.

*“She did some life story work with him, really planning around the loss of his wife as he knew her, which worked very well.”* (Service manager)

One day Mary had a bad fall and broke her hip, and she has struggled with mobility since.

Then the pandemic happened, which has been a difficult time for Mary and Paul.

*“When COVID hit obviously he couldn’t go out and his anxieties were really increased.”* (Service manager)

*“We’ve had this blinking virus, which has changed an awful lot, regardless of the dementia. So, it’s very hard to be that precise about what’s causing what. It really affected their lives, and they didn’t understand why.”* (Mary’s sister)

Staff are now looking to start Paul’s counselling sessions back. They are also supporting him to do more activities outside the house again.

*“I think it’s probably more COVID-related and we’re working on building his confidence up again.”* (Service manager)

He has recently been to a football match and Mary’s sister is planning to invite him for regular visits to her house again.



During COVID Mary's dementia progressed. She started to interact less with people, including Paul.

They still like to remember their wedding anniversary and birthdays and have moments where they connect.

*"He's very loving towards her, but she won't initiate it, because I don't think she's got the capacity to now. But she's aware of him being there, yes, she's aware of him being there."* (Mary's sister)

Because Mary's needs are changing, the service is concerned that she might need to move in the future.

*"The buildings are not really designed for someone with advanced needs. There's no way to get a hoist into her bathroom for example."* (Service manager)

They have started to speak to social work about the changes in the future and will involve Paul when it becomes a more pressing need. They want to offer him the option to stay with her.

*"I see them staying together, and I think it would distress them if they weren't together."* (Mary's sister)

*“Ideally, their future home would be a two-bed place with Paul, if he wants to go with her, and we do involve him in any decision. It will be his decision at that time.” (Service manager)*

