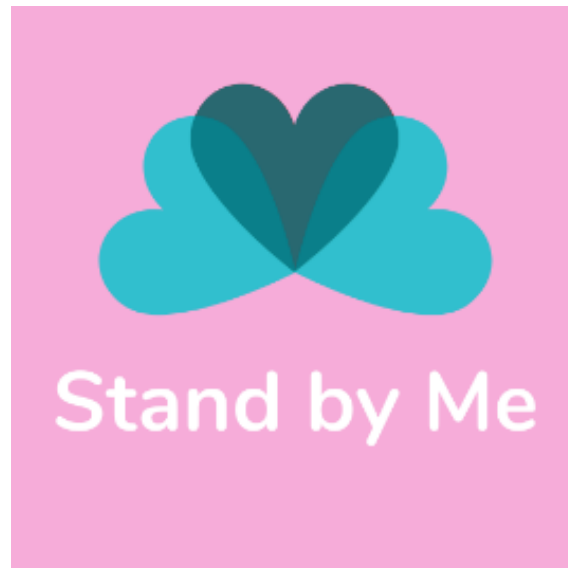


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Story 2: John and Maggie

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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John and Maggie

John and Maggie knew each other for several years before they became a couple.

They lived together with others with a learning disability in the South of England.

“And at first, we were friends and then we become boyfriend and girlfriend, and then after that we become...we got engaged and she became my fiancée and then after that we got married after that. A good few years after that.” (John)

At the place where they lived John and Maggie did not have their own space.

This made it difficult for them to have a relationship and get married.

John and Maggie felt that staff and the manager of the place were not supportive of their relationship.

John and Maggie saved money to pay for a wedding but the service did not allow them to use their money for the wedding.

They were told that they would need to find a place in a supported living service first, where they could have their own rooms.

John talked to his social worker who helped them to move.

They finally had their wedding in 1999, ten years after they first met.

“They said you can’t really get married first, so you have to wait until you get a supported house first. So, we had to wait until we got the [new] place and [that] place really helped us to get married and settle down. I think they do keep people with learning disabilities back a bit, we were planning for a long time. So, it was a bit of a let down at first. It was lucky that we got married in the end.” (John)

John and Maggie celebrated their wedding with friends and family.

“It was a really good wedding day, we enjoyed ourselves. And my mum was alive then. My dad was already gone but my mum enjoyed it. My family was there. All my friends were there, and it was a lovely day. It was on a Saturday, really nice.” (John)

Maggie wore a wedding dress and John wore a suit. *“All suited up.”*
(John)

They went to Brighton for their honeymoon.

“And we had champagne in the room and we enjoyed ourselves.” (John)

They continued to live at the new house, where they had their own room and a little lounge, like a box room. Other people with a learning disability lived in the house as well and people shared the kitchen.

“Had some friends there, they took to me, we had a good laugh. You get ups and downs when you are sharing. I’m more happier now because I’ve got my own flat but them days, we had to share a lot. Even though we had lovely friends it was all...share everything.” (John)

John and Maggie worked and went to college during the week. They enjoyed going out together and doing shopping.

“I used to do different jobs and I used to go to college those days as well, I used to work as well because I’ve always worked, I’ve always liked working.” (John)

They looked after their place and shared cooking and cleaning tasks.

“She helped me, and we helped each other.” (John)

Around seven or eight years into their marriage Maggie started to act differently. She was more agitated and she seemed more stressed.

Someone came to speak to John and told him that his wife had dementia.

“There was a lady, she used to come, I think she was a social worker or something like that. At first, I didn’t take it in first, I was a bit dumbstruck, I said, no, she can’t have dementia. I didn’t know what it was at that time because a lot of people say Alzheimer’s, a lot of people say dementia, and it used to be very confusing for me.

It was very hard to take it all in. Lots of staff tried to tell me but it’s very hard to listen to it if it is your loved one. I actually thought she was going to get better because I didn’t know, because like a lot of things you get better with. I know sometimes cancers and things like that can be difficult, but people do get over them. I thought she will get better...and they kept saying to me, no, she won’t get better because she’s ill and things like that. I’d get all uptight and didn’t want them to say that.”

(John)

Maggie started to need more help because she could get confused and forget things, which was frustrating for her and sometimes made her angry.

John started to help Maggie more. When she got up at night and started wandering around the room he would help her get back into bed.

“I used to say to her, it’s not morning yet, go back to bed and she used to be all right then. I used to talk to her, give her a cuddle and she used to calm down.” (John)

John and Maggie continued to enjoy spending time together and to look after each other.

It was difficult for John to see Maggie being unwell and difficult for Maggie to feel confused.

“We used to have a nice time together, even those times, she used to hold my hand, I used to hold her hand and we used to cuddle and kiss and she’d go ‘sorry’. I’d say, ‘Oh don’t worry about it, it’s all right, it’s not your fault’. And then we’d have a cuddle and then we’d be all right together.” (John)

John and Maggie did not talk about dementia but he found it helpful to speak to staff and his mother.

“They used to say don’t worry, we’ll help you through it. There was a good manager there at the time, she really helped me.

I’d go and see my mum. My mum used to talk to me and help me. And then my mum passed away as well, so it was quite difficult for me.”

(John)

It was hard for John when people said Maggie would not get better.

“I couldn’t really accept it...I didn’t really understand nothing about it. And it was confusing for me as well...it used to make me cry, upsetting.” (John)

John started to see a counsellor which helped him.

“She’d talk to you about your problems and she’d do breathing exercises with you. The breathing exercises, you have to make sure you’re on a beach or somewhere thinking about nice thoughts. Yeah, it’s quite good. All them things did help me.” (John)

Staff also made sure John could spend some time on his own to do things he enjoyed.

“I used to go out sometimes for breathing space for myself and to try and get a bit away from it.” (John)

Towards the end of Maggie’s life, staff would visit John and Maggie in their flat more often. They made sure they were all right, they helped Maggie to dress and wash. Maggie started to use a wheelchair and staff used a hoist to help her get into and out of bed.

John also helped Maggie and cared for her.

“I’d put her clothes on for her, help her, put her trousers on, her tops, her coat on for her. And then I used to feed her sometimes as well. I wasn’t only her husband I was a carer as well.” (John)

Maggie and John lived together until Maggie died.

“I even stopped them from putting her in a home. I said, ‘No, it’s all right. I’ll look after her.’ They said, ‘You don’t have to do it all yourself, we are here to support you’. I’ll be honest with you. I wouldn’t have been able to cope with it on my own. So, I’m pleased the staff was there to help me.”

It was strange, even when I had a break and I was out with the fellas, I couldn’t wait to get back to her. I used to miss her. Because I’d miss all the good times together.” (John)

John doesn’t like to talk about Maggie’s death. He was very sad and needed time to come to terms with the fact that she was gone.

He is now in a new relationship and lives in a new flat.

During the week he goes to college and works at the Co-op.

“Me and my new girlfriend, we are happy, we get on really well. I’ve got my own flat here now and I’m happy now, I’ve settled down again. It took me a long time to build up again though.” (John)

The advice he would like to give other couples in a similar situation is not to be afraid to ask for help and for others to ask couples how they are feeling.

“People shouldn’t be afraid to ask for help. And I think people talking to you more and asking ‘are you all right, how you’re coping’ helps. Because I think talking is a very good thing and the staff always said to me, if you’ve got any problems you can always talk. Because talking is the best...talking and support.” (John)