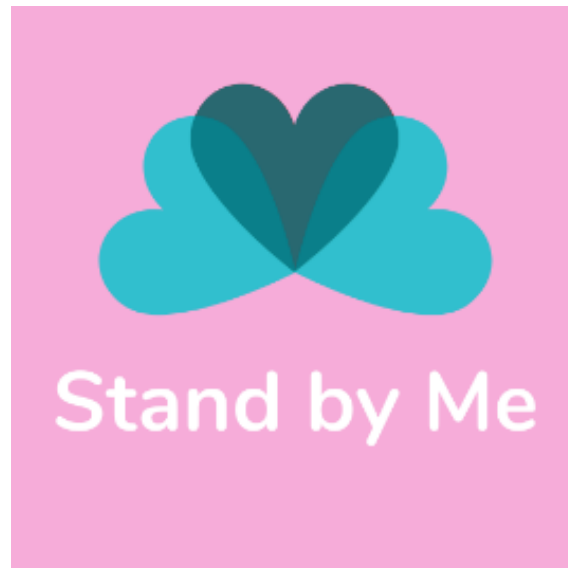


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Story 7: Tom and Rose

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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Tom and Rose

Tom and Rose met at the beginning of the 1990s. They lived in different houses in the same town and were supported by the same service. They met at local activities, and both went to the same day centre.

Tom remembers that at first he lived with several other people in a large house, but then later he shared a house with just one other man.

When this housemate moved out to live together with his girlfriend, Tom and Rose decided that they wanted to live together.

“Subsequently Tom proposed, so they decided to get married. They have been living together since 1995.” (Service manager)

Tom and Rose got married in 2008. Staff were supportive of their wish to get married and helped to organise the wedding.

Rose had a hen party. She and her friends dressed up as the Pink Ladies. She did not have family members who lived close by, but her aunt came to the wedding. Tom’s brother and mother also came.

“I don’t think my mum was very keen. I’m not sure if she was very keen I was getting married or anything like that. But, I mean, she came round to it. It was the staff that helped with the wedding.” (Tom)

They had their wedding reception at a hotel. They celebrated with many people including friends and staff from the service.

“Had a cake, a big one. Aye, it was nice.” (Rose)

Tom and Rose still live together in the same house. Living together gives them more privacy as a couple.

“We don’t have any people barging in or things like that. The staff come over every day at certain times but never stay. They don’t do sleepovers or anything like that. The house is ours.” (Tom)

Staff supported them with some household tasks, but otherwise Tom and Rose were very independent. Rose continued to go to the local day centre and worked at a local café.

Tom worked at different places over the years and provided advocacy work for a number of organisations.

In 2006, he received an award for his advocacy work from the Queen. Tom and Rose travelled together to London for the ceremony supported by a member of staff. They almost missed the ceremony as the hotel had forgotten to order a taxi. Tom remembers:

“She said, oh I forgot. And then one of the men said to me he would go and try and find a taxi. He went out and he never came back. So, we had to go down the road and find a taxi ourselves. Big road...and then, in five minutes we got there. Five minutes, ’cause you only had a certain amount of time. If you weren’t there you wouldn’t be able to get in. So, we only had five minutes spare to get up to the Palace.” (Tom)

Afterwards Tom and Rose went to Harrods to celebrate. They also went to see Chitty Chitty Bang Bang at the theatre.

Then around four years ago, Tom started to sometimes feel sad and low.

“I went to the doctors and had to go to...I don’t even know what it was about ’cause we went to the hospital and went to see this man. He said you’ve got dementia. I didn’t even know what that meant, what it was. He said my memory’s going to go and things like that, when I get older.” (Tom)

Tom has a dual diagnosis of vascular dementia and Alzheimer’s, but he and others haven’t seen too many symptoms so far. Tom continues to be independent without needing a lot of extra support. The main change is that he now needs support with taking his medicine in the morning and evening.

“We just kind of get on with it, you know. I’ve not been that bad yet, I don’t think. We usually have three workers, one in the morning ’cause I have to get my pills and that, ’cause I can’t take the pills myself. So somebody comes in the morning and then sometimes – it could be the same worker, it could be another worker that comes later on. They’ll come maybe from one to four, something like that. And then at night-time somebody comes about seven, eight and gives the pills at night-time.” (Tom)

“You’ve got that diagnosis but the changes haven’t been particularly quick. I don’t think there’s any particular changes.” (Service manager)

Getting the diagnosis of dementia was difficult. Tom was worried how it would affect Rose and their relationship. He felt overwhelmed by a lot of the information and is anxious about what the future might hold.

Staff spoke to Rose about the dementia diagnosis.

Shortly after his diagnosis, the COVID-19 pandemic happened. It was a difficult time for Tom and Rose and both felt more isolated. They are happy now to be able to do more things again, like going to local cafes and out for meals and walks. For their last anniversary, they stayed in the honeymoon suite at a hotel for a night and listened to some live music.

Tom tries to focus on the here and now. But sometimes he gets worried and he feels less confident than before. He says that it is almost like he is waiting for changes to happen and he can get anxious about the future.

Rose tries to reassure Tom and to support him. She tries to be positive and to focus on their life now.

Tom and Rose can talk to staff if they have questions or worries. Staff are there to listen and try to help Tom to focus on what is happening now. Tom and Rose find it helpful to talk to workers they trust. They don't always get on with the same people and are comfortable with different support workers.

They prefer talking to people they know well.

“We’ve got a couple of workers that we could sit and talk to them about things, but there’s some I just couldn’t. I mean, they’ll come and they’ll do what they have to do but I couldn’t sit down and have a conversation with them. Talking to [the Service manager] was good when I first got it.” (Tom)

Tom and Rose have started to make plans for their future care. With help from their workers, they have they met with a solicitor.

“Just when things start going downhill, they’ll have to take over. Medical things or legal things, things like that.” (Tom)

“That’s been part of the conversations that’s been had with Tom about writing down the information that’s important to him. Rose is doing that separately, because that’s another piece of work that’s ongoing and that is important for her.” (Service manager)

For the future, Tom and Rose want to move into a smaller house that doesn’t have stairs.

“I fell going upstairs.” (Rose)

“We’re on the list but don’t know, could take years before we even get another house. Hopefully we’ll get a chance of getting one. The house we’ve got is all right, but it’s too big.” (Tom)

Finding a house that meets their needs has been difficult. They have already viewed a few houses and turned them down. They are currently

on a housing list, but every time they turn down a house they get pushed further down the list.

Staff have talked to Tom and Rose about care homes in case that is needed or wanted in the future. Tom struggles to understand what this means, sometimes he thinks it might be ok but other times he says definitely not and how would this affect his relationship with Rose?

Tom and Rose hope they can go on holidays again in the near future now that COVID restrictions have gone.

