

UNIVERSITY of
STIRLING



Story 8: Adam and Phoebe

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.

For more information, please contact Karen.Watchman@stir.ac.uk

Adam and Phoebe

Adam and Phoebe became a couple in the early 70s when they were just 15 years old. At the time they lived in the Scottish Highlands at an institution for people with learning disabilities.

The institution was open between the years 1968 and 2000. It was one of the biggest learning disability hospitals in Scotland. Over 200 people with learning disabilities lived there and this included children.

Staff at the institution were supportive of Adam and Phoebe's relationship. But, Adam and Phoebe had separate rooms and shared kitchen and living spaces with other people with a learning disability.

"They were very much allowed to be boyfriend and girlfriend back then. As far as I'm aware they weren't like living, they both had their separate rooms. They were just boyfriend and girlfriend but not living together."
(Support worker)

Adam and Phoebe moved out of the institution in the late 1980s.

They moved into a two-bedroom house supported by staff from a local learning disability service.

“Quite a few came from the institution to our service, there was quite a few of them came, so they already all knew each other.” (Support worker)

The house they moved to was located in a town in the Scottish Highlands close to Adam and Phoebe’s families.

They often saw their family and enjoyed being close to them.

“Adam visited his father often and Phoebe had a sister and nieces in the town. So the family were very much involved in their welfare, and they visited them often.” (Support worker)

Adam and Phoebe lived together in their house for over twenty years.

They enjoyed going for walks together, watching soaps on TV and listening to music.

“They both loved a party; they loved music. Well Phoebe, she sang a lot and she loved country music so we’d put on, it was Dolly Parton, Kenny Rogers, Patsy Cline that would be on in the flat while we were doing the housework and that.” (Support worker)

Adam was a big Rangers football fan and he liked watching football in his room. Adam and Phoebe had support to make meals and go shopping. Phoebe also needed some help to get dressed as her mobility was not great.

Adam enjoyed helping Phoebe and looking after her.

“They would sit side by side and hold hands. And he would make her cups of tea, things like that and run after her. She was spoiled rotten, absolutely spoiled rotten. They were just basically like any other couple, you know, they really were.” (Support worker)

Around 2012, staff who supported Adam and Phoebe noticed that Adam was different. He seemed quieter.

“He maybe wouldn’t answer you, and you would repeat things. Or he would kind of look vacantly. It was like he started to just kind of not processing things, whereas before he was pretty sharp.” (Support worker)

Someone from the community health team started to see Adam to try and find out what was happening.

Adam was diagnosed with dementia in 2012 when he was about 55 years old.

The staff were not sure how to explain dementia to Adam. They tried to talk to him about the changes he was experiencing and to reassure him

“You had to sort of gauge it on his level, keep it to words he would understand. I think he knew something was different, but I don’t think he really understood what was happening, which was probably quite scary for him.

We just kind of kept it simple; I think we just explained that things were feeling different and that, you know, just to take his time.” (Support worker)

Staff also talked to Phoebe about Adam’s dementia.

“Again, we tried to keep it at her level of understanding and, Adam’s not well and that he would be a wee bit different.” (Support worker)

Adam did not like leaving the house and he became more insecure about walking and keeping his balance.

Adam and Phoebe started to spend more time inside the house, listening to their music, watching TV and looking at old photographs.

But a lot of their relationship stayed the same. She comforted him when Adam got frustrated or confused.

“She was concerned how he was and like she would put her arm round him; giving him reassurance...they still always sat together side by side. She was letting him know; I’m still here, I’m still with you. As far as she was concerned Adam was still there. She didn’t change towards him.

She still spoke to him the same as she always spoke to him.” (Support worker)

Staff spend more time with Adam and Phoebe to support them.

They made changes to the house to make life easier for Adam and Phoebe.

“There was the nurses coming in and the doctors coming in and we got mobility aids. Phoebe was very happy about that because it helped their daily life. And he got measured and got a new chair to help him. He picked it specifically; and it was blue and he liked that because his football team was blue. It was so he could actually get his feet on the floor and he felt more comfortable.” (Support worker)

Their families were closely involved and supported the couple.

“And we took him over to visit his dad when we could. He liked that, going over to visit his dad.” (Support worker)

Phoebe did not ask staff questions about dementia, but sometimes she would get sad and need a hug.

“I mean we were only too glad to give her a hug or give her emotional support. Sometimes that was enough, just to reassure, give her a hug and say it’s going to be okay Phoebe.” (Support worker)

Staff felt that it was important for Adam to be involved in his care and to give him the time to still do things by himself.

“When Adam dug his heels in, he dug his heels in; and he would do it in his own time. So, it’s just learning to kind of step back a wee bit. It was all about asking his permission. Is it okay if I..., would you like me to...? So that he still felt in control.” (Support worker)

Adam and Phoebe stayed living together in the house until Adam died in 2014.

Before he died, Adam stayed most of the time in his room in his bed and Phoebe would go and sit with him. The doctor often visited and explained to Phoebe what was happening.

“Phoebe would talk to Adam and stroke his head and, you know, which was lovely; so it comforted her. I think the doctor spoke to her and said how ill Adam was.” (Support worker)

Staff supported Phoebe on the day he died.

Phoebe's support worker remembers that even though Phoebe did not ask many questions, she understood what was happening.

"The doctor was coming and I can remember it so clearly as if it was yesterday and we were driving in the car and she said to me; you're taking me out of the way aren't you?" (Support worker)

When they returned Adam had passed away with staff at his side.

"We left her with him for a wee while, she said goodbye." (Support worker)

Family and staff were at the funeral and Phoebe sang a song in Adam's memory.

"Her favourite song was Amazing Grace, so she sung Amazing Grace at his funeral. The whole place was, it was just so emotional. She found this inner strength. We just didn't know was possible." (Support worker)

Phoebe continued to live in their house by herself. She started to go to college and continued to be supported by the same service.

She liked looking at photos of Adam and remembering their time together.

“She had a kind of board and she’d put photographs of family, her and Adam on it. The two of them having a dance at her fiftieth birthday party, that was her favourite photograph. And they both looked just, they were so smart, she looked gorgeous. So that was her pride and joy, this photo of the two of them at her fiftieth birthday party.” (Support worker)

In 2018, Phoebe was also diagnosed with dementia and she died in their home in 2019.