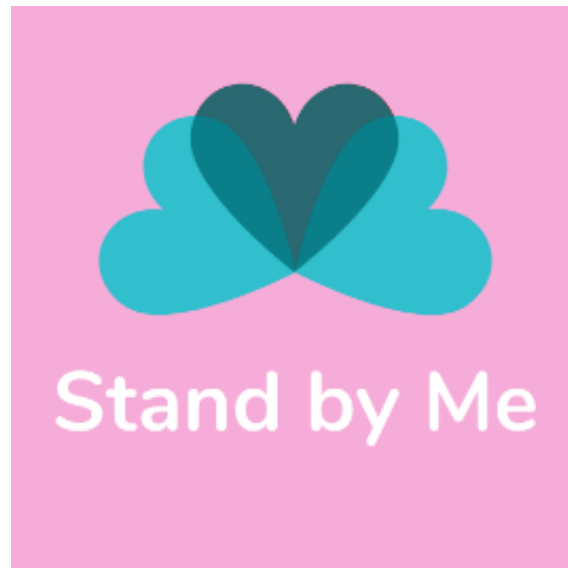


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Story 5: Sarah and Ben

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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Sarah and Ben

Sarah and Ben became a couple in 2007 when Ben moved into the house next to Sarah. They were supported by the same learning disability service. When they became a couple Ben was 29 and Sarah was 38, but their families had known each other since Sarah and Ben were children.

“I had known Ben and his family since he was a baby. So when this all started up...when the relationship started, his family and I, we all knew each other.” (Sarah’s Mum)

“Sarah actually made the first move, she used to go and see Ben for breakfast. At the time Ben was living in a very small bedsit, as part of the same complex with a view to him moving into supported living, and Sarah, as I say, used to go over for breakfast, and used to stay for quite a lot of the day, and the relationship really blossomed and grew.” (Ben’s Mum)

Ben and Sarah’s parents feel that the service was very supportive of the relationship.

“There was never any question they didn’t have a right to be together.” (Sarah’s Mum)

“The big boss as Ben and Sarah used to call him, was incredibly supportive. Because it wasn’t long before Ben and Sarah were living together, and Sarah was spending the night with Ben. So, the interests of the couple very much came first.” (Ben’s Mum)

But Sarah’s mum remembers that some staff could become protective of Sarah, and try to tell Sarah and Ben how to be in a relationship.

“At one point, I said to her, for heaven’s sake, back off, she’s quite capable of telling you if she doesn’t like it, you know. Who else has their

relationship monitored 24-hours a day, because they were still in a care setting.” (Sarah’s Mum)

Sarah’s Mum invited Ben along on a holiday to America a few months after learning about their relationship. When they returned, Ben and Sarah formally moved in together at the beginning of 2008.

“The manager said to me, I don’t think it would matter what any of us say, she’s going to move in there whether we like it or not, she’s quite determined.” (Sarah’s Mum)

At the time, Sarah lived in one of three houses which had been built as residential services. Ben lived in a smaller flat. The service extended the flat to allow the couple to live together.

“What they did to make it into a flat for Ben and Sarah was joining up with the next bedroom in that house. So, they had a bedroom, living room, a bathroom and kitchen.

They had a level of support and familiarity, the place was right in the middle of town, they could walk out everywhere. And there was this 24-hour support on site.” (Sarah’s Mum)

Sarah and Ben were a busy and active couple. Ben went to a supported work placement four days a week, doing gardening and recycling. Sarah had a job in a printing workshop one day each week, art classes and volunteered in a charity shop.

In their free time they enjoyed going into town, visiting the library, going out to eat and doing their shopping.

“So quite an independent and active life really. With a little bit more support round them than many couples would have.” (Sarah’s Mum)

Ben's family lived close by and Sarah and Ben often visited them at weekends. They also joined Sarah's Mum on holidays several times a year.

"We quite often bumped into them in town together, either in Waitrose or in Tesco, shopping, sometimes having a cup of tea out. And the level of independence they found was actually quite remarkable. It brought out a caring side in Ben. It was quite humbling actually to see, in so far as, you know, they would look at each other and there would be the dreamy eyed look between them." (Ben's Mum)

During their relationship, both Sarah and Ben had times when they were unwell and they looked after each other. Sarah developed Crohn's disease, which meant that her stomach often hurt, and she sometimes had toilet accidents.

"Ben was busy looking after her, running a bath, helping her change her clothes. I mean, they really tried very hard to look after each other." (Sarah's Mum)

In 2010, the families had a meeting with the service manager because Sarah and Ben were going to move to a new flat. At the meeting he mentioned that Sarah seemed different. Sarah and Ben's families also noticed that she was forgetting things and was more anxious about change.

Sarah's mum talked to the GP about it, but because of the move they decided to wait with an assessment until Ben and Sarah were settled in their new flat.

Then in 2015, Sarah had problems with her hip and needed a hip replacement. This was a big surgery and Sarah moved home to her mother when she left hospital. Ben came with them for a month and did a great deal to help care for Sarah as she recovered and became mobile. He then returned to their flat and his work.

It took Sarah a while to recover and when she was better she moved back to her flat with Ben. Sarah's mother lived in the North of England, many miles away and so Ben and Sarah were apart for a couple of months.

She continued to struggle to walk and appeared more and more anxious. It became clearer to her family that it was likely that Sarah had dementia.

Her mother was worried about her and felt that the service was struggling to support her medical needs.

“We got her well and she went back to the flat with Ben after the hip surgery. But things went downhill. They made medication mistakes, they weren’t giving her enough support. I kept saying to the manager, you must tell everybody I think she has dementia.” (Sarah’s Mum)

Ben tried to look after her. He found it hard seeing her in pain. Sarah started asking for her mother when upset.

“She missed her mum, she wanted to be with her mum. I think Ben found that very hard, but they were still living together, cuddling up in bed together at night. He showed a side of his character I didn’t know he had, that caring, loving, dedicated support.” (Ben’s Mum)

Sarah’s mother asked social work to get involved. She wanted Sarah to come and live with her so she could look after her. A best interest process started. Social workers talked to Sarah and Ben and their families.

“Each of them got a new case manager. Each of them got an independent advocate.” (Sarah’s Mum)

In the summer of 2016 Sarah moved to live with her mother.

Ben’s mother is not sure how much Ben understood. He did not want to be separated from Sarah and his mother feels that he thought Sarah would eventually get better and move back to live with him.

“I can almost remember his words exactly. Sarah going to live with her mum, when Sarah better, back home to me in the flat.” (Ben’s Mum)

Sarah and Ben's parents asked social services to support Ben to visit Sarah. Eventually, social services paid for a worker to travel with him.

Ben helped Sarah move. It was hard for him to see her go.

"He helped her get settled in and he helped me sort out stuff for her. But of course, coming to live with me she was going to move 300 miles away."
(Sarah's Mum)

He travelled to see her every couple of months.

At her mum's, Sarah started to see health professionals and after some assessments they confirmed that she had dementia.

"We had to show she declined every six months. I don't think we got a definite diagnosis until she'd been with me for at least a year." (Sarah's Mum)

Sarah became less mobile and started to be scared of depths. She needed a wheelchair to move around.

"Ben would do everything he could to look after her and take charge when he came to stay, you know, pushed the wheelchair and so on. And he loved helping with everything. When he came and held her hand and everything, she was so pleased to see him." (Sarah's Mum)

Then COVID happened, which meant that Ben could not visit anymore.

Ben and Sarah saw each other on video calls and Sarah's family sent pictures and videos.

“We had a WhatsApp group. During COVID, of course, the only way we could communicate was on Facetime on the iPad. We would do that. I would video bits of it, send it to Ben and so on.” (Sarah’s mum)

Sarah became more unwell and needed to use a hoist to get in and out of bed. It became difficult for her mother to look after her at home and Sarah moved into a care home for older people.

During the lockdown it was difficult for her family that they could not visit her, but they felt that she was well looked after in the care home.

She stayed in the care home for 18 months and died there in 2020. Until the end she recognised people, and tried to tell them how she was.

“I spent the last 10 days sleeping in her room. Her sister joined me for the last night.” (Sarah’s Mum)

When Sarah died, Ben had not seen her in about a year because of COVID restrictions.

“He couldn’t come for the funeral because her funeral was when we all went back into lockdown. We streamed it and he watched it with his mum.” (Sarah’s mum)

Sarah and Ben’s parents think that towards the end he understood that she was very unwell, but it was difficult for him to talk about it.

“We moved from saying don’t use the word dementia to the point at which I said to the staff, you probably better use the word dementia, and we need to talk about dying.” (Sarah’s Mum)

“He did understand that she was unwell, and she wouldn’t get better.” (Ben’s Mum)

Ben misses Sarah and spending time with her family.

“We still send him messages and tell him what we are doing, and Ben sends us messages too.” (Sarah’s Mum)

He is planning to visit her grave soon.

“Ben wants to put some flowers on Sarah’s grave. He certainly remembers lots of things, and he often talks about her.” (Ben’s Mum)

