

Angela Berriman: My story, my life!

In this case study, Angela gives us a first-person account of her life, detailing her family history, life with her husband, her interests and her healthcare, including her recent diagnosis of dementia.

Nicola, who has supported Angela with her diagnosis, reflects on the importance of telling Angela about the diagnosis and the support needed moving forward.

Profile

Name: Angela

Age: currently 57

Where Angela lives: South/East Midlands

Type of support provided by MacIntyre: Supported Living

“ My name is **Angela Berriman**, I was born on 7 October 1959. I am **57 years old** and I am married to my husband, James Berriman. I am very proud of my marriage and you will hear more about this in a while, but first I would like to share a film with you. This film reflects one of the most important days of my life.

Now that we have watched the film, I would like to share with you a small part of my life story so you can paint a picture of what my life has been like for a lady growing up in the 1960s and going to school in the 1970s. I'll also tell you about my life to the present day, being married and having a big social life and whilst overcoming challenges that I have experienced **living with Down's Syndrome and a new diagnosis of Dementia**.

I will start my story with when I was a young girl.

Before marrying James in 1999 I was known as Angela Hampshire and I was born in London's East End into a Catholic family. I lived with my parents, my brother and my sister. I am the youngest within my family. I went to school in Westham from the age of 5 to 17; while I was at school I presented a bouquet of flowers to President Kennedy's sister Eunice Kennedy Shriver when I was 5 years old - I am very proud of this!

Another big event is visiting Buckingham Place in 1983. I was 24 years old at this time and I watched my father receive an OBE. I have photos of these events to remind me. After my school days I continued to live with my parents. My father sadly died at which point myself and my mother moved to Watlington to be closer to my sister.

My mother died in 1995. Two years before this I moved into my home at MacIntyre and have been happy here ever since. I lived in a shared house for many years with people



who I became good friends with, but now I **live as independently as I can** with James in our one bedroom flat.

I have spent time learning in adult education attending college courses and have also **spent time training others about what it's like to have a learning disability**. I would stand on stage with my husband and feel confident in doing this.

I work very hard Monday to Friday. I have always had a full rota but as I am getting older I have less busy days but **I am still out and about lots**. One thing I have done for many years is working in a busy bakery, sometimes with my husband.

I am not over keen on sports and exercise as when I was a young girl I broke my leg and I worry still that I may cause damage to it.

Interests I have now are:

- Puzzle books
- Watching television
- Holidays
- Spending time with family and visiting my sister in my spare time
- Using my computer

My **health has generally been good over the years**. I am prone to ear infections but I once visited the doctors about it and it was taken care of.

However, I have seen a difference in my health over the past few years. This has raised concerns with people that help support me so **I have been visiting the doctors**

more regularly. I was being told that I wasn't remembering things like I use to and I was also showing signs of disorientation. I had a baseline assessment completed back in 2014, this happened as MacIntyre felt the importance to complete a baseline assessment for all people supported in the local area, following what we had learned and experienced when receiving Alison's diagnosis. My staff continued to monitor and record any changes that concerned them about my health and wellbeing. **Things did start to change rather fast and after more visits to see my doctor, the outcome of this is that I am now living well with dementia.**



I have had lots of support since my diagnosis and small changes are happening at home to support me to **continue to be as independent as I can be**. I spent time with James trying to understand what dementia is and talk about what's important to us both as a married couple. One thing that came out of these meetings is **the importance of staying together**. We would talk about lots of things but always end up back to this.

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Nicola's reflection on Angela's diagnosis

I have known Angela for many years and when I was asked to work closely with the couple I felt honoured. My role was to facilitate meetings for Angela and James and to **be the couple's voice** if they needed me to be. The first thing I thought was that Angela hadn't yet been told that she has dementia and that it was important for her to know this, so I planned to have honest meetings about what's happening to Angela. I thought about how I can have conversations about her diagnosis with her and James without either of them knowing what dementia is or that fact that Angela is now diagnosed with dementia and I thought... I can't. **They must know.**

Everyone in Angela's close circle was invited to the meeting. I spoke with Angela, James, their families and Angela's staff and we all arranged with Angela's Doctor that she would talk face to face with Angela and James and explain to them both that Angela has a **diagnosis of early onset dementia**. We arranged a meeting to directly tell Angela that she has dementia. The reason being is that I was planning on working closely with the couple to support them with this diagnosis, as this was vital to carrying out meaningful future conversations.

The day came and people that are important to Angela were present to support her with the news and to ask the doctor questions if Angela needed support in doing this. The doctor started to talk and I was prepared to hear the words 'Angela you have dementia' but instead I heard the doctor say 'I don't feel that using the "D" word is necessary.

The meeting carried on and Angela and James left none the wiser and not understanding the diagnosis or reason for the meeting. I had a conversation with family and staff and we decided that we would have a conversation with Angela and James to talk them through Angela's diagnosis, to make sure it was understood and that the right support was offered and put into place. Even though these conversations are difficult, Health Professionals need to **take the time to explain a person's diagnosis with them** (if they wish to know it) and should discuss it in a way that makes sense to that person.

Since this meeting, we have spent time with both Angela and James to support them with any challenges they have faced and continue to face. Meetings have taken place as a couple but also we are aware that **James needs extra support** so I have met with him so he has the time to off-load to me as I know he finds this hard to do in front of his wife.

The teams that support Angela have made adaptations to her flat to help orientate Angela within her home. MacIntyre is currently working two full-time waking night support staff into Angela's home. We hope this will reduce the amount of incidents that Angela could have in the future as Angela has a tendency to get up in the night and we feel this isn't safe whilst her and James are alone at night.

MacIntyre will continue to support Angela and James and **keep the couple at the centre of their care and wellbeing.**

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