MacIntyre
Providing support...your way

ANGELA BERRIMAN - MY STORY, MY LIFE

Angela Berriman: A story of a dementia diagnosis

To prepare for Session 1 of the Learning Disability and Dementia training from ARC England and MacIntyre, please can you:

1. Watch this film of Angela and James talking about their life together: https://bit.ly/4y0RXX9

2. Prepare an answer to this question: What is the one message you take from this film? (We will be asking learners to share their answers during the training).
3. Read the information below where Angela talks about her health and Nicola reflects on Angela's dementia diagnosis.
4. Prepare answer to the 3 questions at the end of this document (We will be asking learners to share their answers during the training).

Angela - in her own words - talking about her health: (Shared in 2017)

''I had a baseline assessment completed back in 2014. This happened as MacIntyre felt that it was important 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 (https://www.macintyrecharity.org/our-approach/resources/alison-the-emotional-impact-of-dementia-on-relationships/) . 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've 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."

Nicola's reflection on Angela's dementia diagnosis: (Shared in 2017)

"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 been told about her dementia and that it was important for her to know this, so I planned to have honest meetings about what was happening with Angela. I thought about how I could 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.

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 young onset dementia. After this, I would work closely with the couple to support them with this diagnosis and have meaningful future conversations.

The day of the meeting came and the 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.

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 diagnosis conversation 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 we are also 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 adaptions to her bungalow to help orientate Angela within her home. MacIntyre have two full-time waking night support staff in Angela's home in the hope we can reduce the amount of incidents that Angela could have in the future. 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."

Update as of 2026

Update as of 2026:

Angela and James eventually moved from their own bungalow (Supporting Living) into residential support. MacIntyre continued to support Angela through to the end of her life. Angela sadly died in 2021. James has remained within MacIntyre, although he now has dementia himself.

Questions:
(Please prepare answers to these questions to share during our training session)

1. Angela tells us that she had a baseline assessment completed in 2014. Why would this have been important during the diagnostic process for dementia?

2. What was the impact of the advocacy from MacIntyre staff on Angela's diagnosis and support?

3. How would you describe best practice support for James during Angela's life with dementia and after she died?