The Story of Alison’s Life

This is Alison’s Story. MacIntyre supports Alison and she has Down’s Syndrome and a diagnosis of dementia.

Her story is one of relationships and the emotional impact that dementia can have on friendship. Alison has a really close relationship with Rachel, her best friend who she also lives with.

Alison has always been a really social person, enjoying the company of others. A big part of Alison’s life has always been socialising, in particular she enjoys dancing and football. Growing up as a child, Alison always wanted to wear football shirts, and still does enjoy wearing her favourite kit – Chelsea - proudly.

A big part of her life was working at MacIntyre’s Café and Bakery. Alison used to bake cakes and weigh ingredients; even though she always worked really hard, work was a real social event for her and a hub of friendship where she worked and built strong relationships over many years.

Alison still visits MacIntyre’s Café regularly and also attends MacIntyre’s Memory Café on a monthly basis – she enjoys having a cup of tea and cake and the music around her. Both of these activities provide an opportunity to see her friends and reconnect with those treasured memories.

Family has also been extremely important to Alison. Her mum used to volunteer at MacIntyre but sadly she passed away prior to Alison’s dementia. Alison’s dad is now in his 90s and in a care home, but Alison is still visited by her brother and sisters.
Alison’s diagnosis

The diagnosis took a long time and a lot of information got missed in translation, but staff noticed subtle changes in her. Health Professionals saw Alison’s learning disability first, and without evidence, were not moving forward in a diagnosis of dementia. She was also young to receive her diagnosis – only in her early - mid 40s – but as we know people with a learning disability are more likely to get dementia at a younger age.

Within MacIntyre, we have noticed hesitancy amongst Health Professionals in diagnosing a person with dementia if they have a learning disability. To combat this, we have been reviewing how we record health across the whole of MacIntyre to ensure we are contributing our part towards gaining a timely diagnosis – which we all know is so important.

After Alison received her diagnosis, her health has deteriorated quite quickly – and five years ago Health Professionals said that she only had a couple of years to live. We fought on behalf of Alison to have her stay in her own home; this is where her friends are, where her support is and where her heart is.

Sarah’s reflection of Alison’s diagnosis

I visit Alison as often as I can and she is looking well, most recently I visited her last week. When I speak with her and Rachel, it is so clear to see how strong their bond is. They have been friends for a lifetime, and the diagnosis has been a hard time for them, as it would be for any of us. Rachel often shares that she wishes the dementia would go away – don’t we all?

If you want to find out more, our Registered Manager, Sarah Lancaster has made a series of films that resonate closely to this topic. We have 6 films that overall cover the Emotional Impact of Dementia on Everyone. They can be found on our website, and are a really fantastic resource to share with staff.

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