



MacIntyre Families: The Story of Alison from her Sister Sandra



Alison lived within MacIntyre services for approximately 35 years . She was one of the first people to move into The Haddon's residential service in Milton Keynes. Alison developed dementia when she was in her early-to-mid 40's, and died when she was 53 in 2017.

One of Alison's sisters, Sandra, was interviewed for this case study.

What we have done

Support from Haddon's staff: Sandra feels that Alison, along with herself and other family members, were very well supported by MacIntyre throughout Alison's life. Even when the local authority wanted to move Alison to an older peoples nursing home (after she was diagnosed with dementia), the view from The Haddon's staff, and supported by Alison's family, was that, "This is Alison's home, this is where she should be."

The Dementia Project: Sandra and her family found out about the Dementia Project not long after it began in 2016, the staff at The Haddon's kept them in the loop and, they obtained information from MacIntyre's newsletters and other useful information.

Sandra and her family felt that Alison wasn't just a member of their family, but of the MacIntyre family too!

Support through EOL: In the months before Alison died she had regular hospital visits, often due to her epilepsy, but Sandra reports that staff had a clear process to manage Alison's epilepsy and that this enabled them to correctly decide whether an ambulance was needed or not. MacIntyre staff were heavily involved in Alison's care and support during any inpatient stays, including her end-of-life care.

Bereavement support: Sandra and her family felt that Alison wasn't just a member of their family, but of the MacIntyre family too, and they were grateful for MacIntyre's involvement in Alison's funeral. Half the church congregation were from MacIntyre, and in the weeks afterwards, MacIntyre arranged a memorial event for people who couldn't attend Alison's funeral.



What did we learn?

The importance of tailoring support for families:

Sandra reports that MacIntyre adapted their support for the family depending on individual needs. As a nurse, she felt well-equipped from her professional background to understand Alison's health and care needs, so staff tended to only give information when she wanted to know more, whereas staff offered more in-depth support to other family members if/when they needed that input.

Positive impact of involving families in the Dementia Project:

By knowing the people we support well, and choosing to highlight Alison's story through our Dementia work, we've not only created a positive educational experience for anyone who learns about Alison's life, but also enabled Alison's family to feel that her story can help others.



You can watch Alison's film here: <https://www.youtube.com/watch?v=Y3igyCG5O-8>

Support through EOL: Although Alison died in hospital, she was never alone and MacIntyre staff were very much part of her End Of Life - a fact noted by the senior staff nurse who spoke to Sandra about how impressed she was with MacIntyre's team.

It can be an emotional rollercoaster for staff to support someone so well-known and loved within MacIntyre through the end of their life, staff rose to this challenge with exceptional strength, showing kindness and compassion that was noted by Alison's family and other professionals caring for Alison. The skills learnt and the pathways that were followed will undoubtedly benefit other people supported by MacIntyre and, thanks to the MacIntyre Dementia Project, wider health and social care organisations can learn from those experiences too.



“Staff rose to this challenge with exceptional strength, showing kindness and compassion that was noted by Alison's family and other professionals caring for Alison.”

What are we pleased about?

Support for Alison's father: Sandra speaks particularly warmly about the support their father received. Sadly he died in January 2018, aged 95, and so we were unable to interview him for this case study, but Sandra reports that although their father struggled with Alison's ageing and increasing health deterioration (their mother passed away over 10 years ago), MacIntyre staff were exceptionally supportive towards him.

Their father had his own health concerns in later life, and found visiting Alison increasingly difficult, but MacIntyre supported him through the Area Manager (Sadie Scott) regularly speaking to him on the telephone. Sadie also visited Alison and Sandra's father in his care home and attended his funeral.



What are we pleased about?

Support from Haddon's staff: As a nurse for many years, Sandra says of The Haddon's: she has never seen a care and support service that is so all-involving, caring, and completely focused on looking after the people within the service.

Alison's film: Alison's story and legacy is shared often and the film she made with her best friend Rachel (who is now employed as a Health, Dementia & Wellbeing Assistant). Alison's family consented to the film being made and Sandra says that they were very happy with the final video. In her professional nursing role, Sandra shared the film with colleagues at work, including the dementia specialist in her Trust, and all were very positive about the film. Overall, Alison's family are proud of the continued impact and legacy her involvement in the MacIntyre Dementia Project has secured. "It's so important to share stories like Alison's so that everyone can learn from them and develop their services to meet the needs of the people they are supporting. In the end, if it helps other people then that's great."

"I have never seen a care and support service that is so all-involving, caring, and completely focused on looking after the people within the service."

The MacIntyre Dementia Project: Although Alison developed dementia before the MacIntyre Dementia Project began, the additional resources the MacIntyre Dementia Project provided to Phase 1 areas were utilised by the team supporting Alison. The resources created include an e-learning modules on dementia as well as epilepsy, which would have helped staff provide the epilepsy management noted by Alison's sister Sandra. The 7-module theme on End of Life care also includes extensive information about supporting the people close to a person during EOLC and following a bereavement, which are again noted by Sandra of being areas where MacIntyre staff excelled. These are now available freely on our website for all to access via: www.macintyrecharity.org

What are we concerned about?

The risk of making Alison's story public:

By involving someone with advancing dementia in the MacIntyre Dementia Project so publicly, even with consent, there was no guarantee that the impact would be welcome long-term, not least of which since Alison has now died. However, Sandra reports a view that:

"We can only make things better if we make more people aware. The film and resources will hopefully benefit many others in years to come."



What next?

For MacIntyre and the wider health and social care sector: To ensure that the knowledge gained from supporting Alison and her family isn't lost. Sandra's message is:

“Keep going, keep doing what you did for Alison for others who need it.

What was happening with Alison (when she developed dementia) was new to MacIntyre, but they went out and found information and gave the best support possible.”

Coming from an NHS nursing background, Sandra reports that it is wonderful to see MacIntyre's person-centered approaches, an example that she would love to see replicated in all health and care services.

For other families: Sandra's advice:

“Don't be afraid to ask for information or advice.” Sandra said her wish for other families going through the same experiences is, “That everyone could have what Alison had,” adding, “I can't speak highly enough of MacIntyre”.




With thanks to **Beth Britton**, consultant to MacIntyre's Health, Dementia and Wellbeing team, for authoring this case study
<http://www.bethbritton.com>

Get in touch!

 01908 230 100


 health.team@macintyrecharity.org

 www.macintyrecharity.org

 www.facebook.com/MacIntyreCharity1

 uk.linkedin.com/company/macintyre

 www.youtube.com/providingsupport

 @meetmacintyre

 @DementiaLD & @HealthLD



MacIntyre
Wellbeing for Life
Keep GoingDon't Stop!

