



MacIntyre Families: The Story of Jo and Jess

Jess is 35 and has a learning disability that was first noticed by her parents in her childhood. Jess currently lives on her own in a housing association property where MacIntyre provide regular support classed as independent living with care. Jess lives about 40 minutes from her mum, Jo. Jess has a brother, aged 40, and regular contact with her dad, who lives fairly close to Jess.

Jess' grandmother (Jo's mother) lived with dementia. Jo and Jess are well-known authors, having published a series of books about 'Jess The Goth Fairy'.

Jo was interviewed for this case study.



"I know that whatever the problem is, someone at MacIntyre will be able to help!"
- Jo Allmond, Jess's Mum



What we have done?

Dementia Special Interest Group: Jo and Jess' first contact with the Dementia Project was through attending the October 2016 MacIntyre Dementia Special Interest Group. At that meeting Wendy Mitchell, who is living with dementia, gave a talk about her personal experiences which was transformative for Jo and Jess, helping Jess understand what dementia was and how the symptoms of dementia were affecting her nan. In talking about dementia now, Jess recounts a quote from Wendy's talk, where Wendy referenced TV programme 'The Great British Bake Off', saying: "You'll all know who won it next week, but I'll forget."

Access to Wellbeing for Life: Jo has access to the Wellbeing for Life toolkit, which she describes as, "Very good. Something to dip in to when I need it."

Supporting Jo and Jess: When MacIntyre started providing support for Jess, it was only 12 hours a week, which Jo says didn't go far enough. Now Jess receives 30 hours of support a week, which Jo says has, "turned our lives around."



However, living alone Jess often gets lonely or anxious in the evening, sending lots of texts to Jo for emotional support. Jess wants to remain living independently, so additional emotional support is being sought to alleviate her loneliness. Jo admits, "Sometimes I've rung MacIntyre in tears, but I know that whatever the problem is, someone at MacIntyre will be able to help, be it the Health & Dementia team, Emma (Emma Killick, Director of Adult Services) or the local MacIntyre support staff. As a whole package, it's made a huge difference."

Making connections for Jo and Jess: MacIntyre invited Jo and Jess to give a talk at the 2017 Dementia Congress as part of the MacIntyre's stream showcasing learning disabilities and dementia. Jess spoke about the effect her nan's dementia had had on her, and Jo spoke about being a family carer with multiple responsibilities.

Jo described these as living with the 3 D's - Dementia (Jo's mum), Disability (Jess) and Depression (Jo's husband). Due to the success of Dementia UK Congress, Jo and Jess were invited to speak at a bereavement conference in Bradford in the summer of 2018.

In addition, through their continued involvement with the Dementia Special Interest Group, Jo and Jess met Suzy Webster (who is caring for her mother with dementia) and this led to Jo and Jess attending the 'My Home Life' conference in Wales in March 2018. Jo and Jess are also part of MacIntyre's Co-production Steering Group, with Jo representing the views of family carers.

What did we learn?

The importance of communicating about MacIntyre's dementia work: Jo can't recall exactly how she came to hear about MacIntyre's Dementia work, but it is likely to have come from conversations with MacIntyre staff or from reading internal or external publications. The huge impact attending Dementia Special Interest Group meetings has had on Jo and Jess highlights the need to always ensure that communication reaches far and wide. As the parent of a 30-something adult who, whilst receiving support from MacIntyre isn't in any way suspected of developing dementia, Jo, and indeed Jess, wouldn't have been a 'core' audience for the MacIntyre Dementia Project, but it's vital to remember that dementia reaches far and wide into families and beyond just the people a social care provider like MacIntyre directly supports.

"I wish I'd got in touch with MacIntyre sooner about dementia." - Jo Allmond

The power of lived experience: Jo and Jess have brought a very important perspective to MacIntyre's dementia work, showing the often unseen difficulties when a person with a learning disability has a family member living with dementia, and the challenges faced by a parent who, as well as supporting their adult daughter, has also supported their ageing parent with dementia and a spouse with depression. Highlighting these multiple caring responsibilities, that go beyond the 'sandwich carer' role that is more widely known about, is important to help bring the difficulties faced by individuals like Jo to the forefront of discussions about family carers.



What are we pleased about?

Helping Jess understand dementia: Jo credits attending the Dementia Special Interest Group with helping Jess understand dementia, “If we hadn’t been coming to the meetings, which enabled Jess to talk about her nan, it would have been incredibly difficult for her to cope with the visits to her nan. The more Jess understood, the easier it became for her.”

Jess’ awareness-raising work: Jess has become a Dementia Friend (as has Jo), and given talks in schools about dementia as well as to local NHS services. Jess has made a video and a poster about the care and support she wants in care settings and hospitals. Jess has also worked with ‘Safe Places’ to help shape their work for vulnerable people. Jo is certain that all of this wouldn’t have happened if Jess hadn’t absorbed what she has at the Dementia Special Interest Group meetings.

Jo and Jess’ book: ‘She’s Still My Nan’ in the Goth Fairy series is specifically based on Jess’ nan living with dementia, the creation of this book came out of attending the October 2016 Dementia Special Interest Group meeting and getting to know Wendy Mitchell. Jess has since gone on to write more books the latest being ‘Jess Guides the Way’.



“MacIntyre have given me a career I never thought I’d have - books, speaking and awareness-raising.” - Jo Allmond, Jess’s Mum

Supporting Jo to understand her mum’s dementia: Jo’s mum had already been living with dementia for around 8 years before Jo came to the October 2016 Dementia Special Interest Group meeting. Jo felt that she was fairly knowledgeable about dementia, but admits to having significantly enhanced her understanding since becoming involved with MacIntyre’s dementia work. Jo says: “I learnt to accept mum.”



Supporting Jo to have a life outside of being a family carer: When Jess was younger everything Jo did had to fit around Jess’ needs. Since becoming involved with the Health, Dementia and Wellbeing team Jo says, “MacIntyre have given me a career I never thought I’d have - books, speaking and awareness-raising.”

What are we concerned about?

The risk that we miss supporting a family experiencing dementia: Even the most pro-active social care provider cannot know everything about every person they support and every family member connected to that person. Jess’ grandmother lived with dementia for approximately 5 years undiagnosed and 5 years diagnosed. Jo and Jess have only had input from MacIntyre within the last 2 years. As Jo says, “I wish I’d got in touch with MacIntyre sooner about dementia.”



What next?

Jo and Jess' dementia work continues: Jo and Jess have plans to do more challenges and fundraising initiatives for charity, as well as giving more talks and adding to the 'Jess The Goth Fairy' series of books, with a portion of the profits from the books going to MacIntyre. Jo also wants to begin a blog, and will be talking to MacIntyre's External Consultant Beth Britton, who is also a blogger, about this.

Promoting the Dementia Project: As a result of their awareness-raising work, Jo and Jess have met many people who haven't made the link between learning disabilities and dementia until they hear about MacIntyre's Dementia Project. Jo is firmly committed to continuing to promote the work MacIntyre are doing saying:

"It's wonderful to watch what MacIntyre are doing with this work."

Supporting Jess: MacIntyre will continue to provide Jess with independent living support, and support for her parents and wider family.

Continuing to support Jo: As a result of working on this case study, Jo highlighted that multiple medication use was something that she was concerned about in her family. We highlighted MacIntyre's published poly pharmacy resource to Jo to help support her understanding of this issue.



With thanks to **Beth Britton**, consultant to MacIntyre's Health, Dementia and Wellbeing team, for authoring this case study
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Keep GoingDon't Stop!

