



MacIntyre Families: The Story of Moira and Shared Lives Carer Tina



Tina is Moira's MacIntyre Shared Lives carer. Moira had known Tina for 8 years, initially because Moira was a customer of Tina's business. When Moira's father, Stan, died and the health of her mother, Dorothy, deteriorated, Moira started to work voluntarily for Tina, and from then on they became friends.

As Dorothy's health continued to decline, Moira began to stay with Tina and her husband Jeff for a night's respite a week, and eventually Moira moved in with Tina and Jeff when she was 53. Although separating from a daughter she'd supported for 50+ years was very difficult, Dorothy said at the time of the decision for Moira to move in with Tina: **"I can't think of anyone better."**

Moira had a diagnosis of learning disability and dementia, and died when she was 66 in 2019.

Tina was interviewed for this case study.

"I would do all the training again if the opportunity arose, it was that good." - Tina

Shared Lives - A family model of care and support: Although formally we describe Tina as a Shared Lives carer, Tina very much views herself as Moira's friend, and Moira as one of her family. Tina says, "I did for Moira what I would do for my own flesh and blood."

Bringing Moira into her family home was the first time Tina had ever experienced Shared Lives. She describes this as being a, "complete change in my life." Tina goes on, "you take the full responsibility for what is involved, fighting for that person and what they need."

Tina and Jeff have since gone on to welcome Ami and Hannah into their family home as part of the Shared Lives scheme, as well as providing respite for individuals being supported by other Shared Lives Carers.

With understanding still patchy about how much of a family-orientated model of care Shared Lives is, Tina's view is very much, "Moira is my family."

What we have done

Support from the MacIntyre Dementia Project: Tina attended two Phase 1 Roundtables delivered by the Dementia Project team, which gave her an important opportunity to receive peer support from MacIntyre staff, many of whom work on the frontline in residential services. The Roundtable format also enabled Tina to raise questions and queries relating to Moira's needs at that time. In addition, Tina and Moira were visited at home by Beth Britton, MacIntyre's External Dementia Project Consultant.



Tina has had access to the Wellbeing for Life toolkit, and received other ad-hoc support from the Health, Dementia and Wellbeing team via email, phone calls etc. Tina has also attended a few MacIntyre Dementia Special Interest Group meetings. Tina has always welcomed the opportunity to be involved in the Dementia Project and have access to the additional resources, commenting, "I've always felt if I needed more training it would have been there."

What did we learn?

Providing knowledge is key: Tina was hungry for information to best support Moira. By giving Tina training and support, MacIntyre have enabled her to care for and support Moira far better than she otherwise might have. Access to MacIntyre's various resources has empowered Tina, giving her confidence and answers to questions. It's enabled Tina to advocate more effectively for Moira with external health and social care professionals, and also equipped her in her role helping Moira's mum to understand Moira's dementia and how it has/will progress. As Tina says: "I would do all the training again if the opportunity arose, it was that good."

Relationships are vital to the success of Shared Lives:

Moira and Tina's story is one of a deep friendship developed before they entered into the formal Shared

a strain on relationships, but through MacIntyre nurturing Tina in her Shared Lives role, the relationship between Moira and Tina only deepened, providing hugely positive outcomes for both of them.

Shares Lives is about the wider family: Although Tina was Moira's formal Shared Lives carer, it's important not to forget the important role of Tina's husband, Jeff, who had also developed a really positive relationship with Moira and Dorothy. Equally, while Tina and Jeff's grown up children don't live in the family home any more, they both came to see Moira as someone to care for in a sibling-type relationship, particularly since Moira developed dementia.

"I do for Moira what I would do for my own flesh and blood." - Tina



What are we pleased about?

How we've supported Moira and Tina: As Moira's dementia progressed, Tina had been supported by MacIntyre to provide optimum care and support. Tina has coped well with different challenges, many of which were new to her at the time, and remains a committed and highly-skilled Shared Lives carer.

An example of this support in practice is a conversation Tina had with Beth Britton, MacIntyre's External Dementia Project Consultant, about poly-pharmacy. Armed with this information, Tina had Moira's medication reviewed and had felt confident enough to talk to other people about poly-pharmacy, prompting some individuals to then have their own medication reviews.



How Tina's supported Moira's mum: Whilst some Shared Lives carers don't have significant contact with the family of the person they support, Tina has a close relationship with Moira's mum Dorothy. Tina has supported Dorothy in numerous different ways, including taking her on holiday, and Dorothy phoned daily. Dorothy saw Moira regularly, often facilitated by Tina and Jeff, who would pick Dorothy up and bring her back to their house.

Tina's award: Tina's remarkable development as a Shared Lives carer didn't go unnoticed. Tina won a regional care award in 2017 and says that had she had a chance to give a speech, she would have said, "I wouldn't be standing here now without the training and support from MacIntyre in relation to dementia. That support prepared me to understand Moira and what she was experiencing, and how her dementia progressed."

What are we concerned about?

Keeping connected to Shared Lives carers: Remaining connected to Shared Lives carers can be more problematic than with MacIntyre's workforce as Tina isn't part of the training and development systems that staff are. MacIntyre have largely overcome this barrier through individual staff members being proactive in involving Tina in the Health & Dementia Team and inviting her to events/meetings, but the risk of overlooking individual Shared Lives carers is something we need to be aware of.



Technological issues: Tina's thirst for knowledge meant she absolutely had to have access to the Wellbeing for Life toolkit, but actually using this platform hasn't always been easy for Tina. MacIntyre have learnt that issues with the technology that runs the e-learning means that people accessing it without a MacIntyre email address can sometimes have problems.

Tina's experiences with some external professionals: Some of the interactions Tina has had with external professionals who don't view Shared Lives as a family model, but rather as another form of formal care provision, had been very upsetting for Tina and Moira. Assessments and meetings in their home have sometimes turned life upside down, and it's clear that more sensitivity and respect for their family life is a key learning point for all professionals involved in supporting Shared Lives families. In Tina's words: "Professionals just don't always get it".



What next?

Moira's health deteriorated towards the end of 2018 and sadly Moira died in February 2019. Tina was committed to supporting Moira through to the end of her life, and this was very much what Dorothy wanted for her daughter as well. Tina was aware she needs to upskill herself in end-of-life care, and had been working on the Wellbeing for Life EOL modules, although she felt some of the content is more appropriate for residential services than Shared Lives.



Tina wanted to bring as much enjoyment and stimulation into Moira's life as possible, and ensured she got out and about with Moira more during the spring/summer of 2018.

Tina's highlighted that she is an emotional person, sometimes questioning if she needs to, "turn her emotions off." Ensuring MacIntyre support Tina's own wellbeing, most notably through the close relationship that she has with the local MacIntyre Shared Lives Manager is key. We know that if we support Tina well she would in-turn continue to do likewise for Moira.

To promote Shared Lives: Tina's view is that, "Shared Lives needs to have more awareness of what it is and what it does." To this end, Tina takes every opportunity she can to champion Shared Lives, "You have experience of your own children growing up, you have all that knowledge, and with the specialist training that is offered, Shared Lives in the perfect next step for your family."

Tina concludes, "If I didn't believe in MacIntyre, I wouldn't have introduced so many people to their Shared Lives."



With thanks to **Beth Britton**, consultant to MacIntyre's Health, Dementia and Wellbeing team, for authoring this case study
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