The story of Martin's life: a summary

This case study tracks the life of Martin, who died aged 67 having spent 14 years in MacIntyre services, firstly in supported living and then registered care. Martin developed Alzheimer's disease 10 years before he died, and lived comparatively well thanks to the continuity of care he received from MacIntyre staff and the extensive support from his multidisciplinary healthcare team.

Martin benefitted from being able to move within MacIntyre to a care service that could support his growing needs as his mobility and life skills deteriorated, and although Martin had numerous health problems in the last 3 years of his life, the knowledge staff had built up in relation to Martin, the good working relationship with his family, and the breadth of access to external healthcare professionals undoubtedly helped to give Martin's life both quality and longevity.

Of particular note in this case study is Martin's end of life care, which was delivered exclusively within his MacIntyre service and is an excellent example of seamless working between health and social care professionals. Martin's wishes, and those of his family, were faithfully followed and we believe Martin experienced what could be termed 'a good death'.

A summary of Martin's health history:

- Martin was born with Down's syndrome
- Martin was diagnosed with Alzheimer's Disease in 2006
- Martin developed epilepsy in the years following his diagnosis of Alzheimer's Disease
- Martin had sight problems (Martin's father was blind)
- Martin had hypothyroidism (an overactive thyroid)
- In the latter years of his life, Martin became immobile, doubly incontinent, was diagnosed with dysphagia and had very fragile skin, putting him at risk of pressure ulcers
- Martin was prone to UTI's and chest infections

Significant factors that enabled Martin to have 'a good death':

- Plans were put in place early and the staff team were as prepared as they could be
- The wishes of Martin and his family were followed, ensuring that Martin was able to die in his and their place of choice, rather than in an impersonal and busy hospital environment
- Martin had his family's support, and although they weren't present at the time he died, they had visited him very recently
- Staff supporting Martin knew him very well, and were able to use their knowledge of Martin to provide optimum support, communicating with him and reassuring him
- Support for Martin and his staff team from Martin's GP, district nurse team and local palliative care service was excellent

MacIntyre Dementia Project

DAA Dementia Action Alliance

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Profile

Name: Martin

Age: 67 (when he died)

Where Martin lived: South/East Midlands

Type of support provided by MacIntyre:
Registered Care

"Martin was kind and caring with a gentle nature and was considered a real gentleman"

About Martin

Likes and dislikes, hobbies and interests:

- Martin loved football and was an avid supporter of Ipswich Town Football Club
- Martin liked to listen to Cliff Richard and Elvis on his stereo and watch Grease on DVD
- Martin liked to go out with friends and family when they visited him
- Martin enjoyed a cup of tea and one of his favourite foods was ice cream

Martin's character:

- Martin had a sense of humour and an imaginative mind
- Martin was known for his ability to make others smile, for his own big smile and laugh
- Martin was kind and caring with a gentle nature and was considered a real gentleman

Personal history:

Martin was born with Down's Syndrome and was one of three children in his family, alongside his sister and brother. When Martin was 3 years old he went to live in a care home, returning to live with his parents when he was 14. Martin's mum died in 1980 and his dad died in 2000. Martin went to live with his sister, but she died in 2002 and he then moved to a care home. Martin left the care home after one of his cousins arranged a place in a MacIntyre supported living service. Martin's brother died shortly after Martin's move into this supported living service, making his only surviving relatives his two cousins.

History with MacIntyre services:

Martin had lived within MacIntyre services since 2002, firstly in a supported living service. When the supported living service could no longer meet Martin's needs as his dementia progressed (Martin was diagnosed with Alzheimer's disease in 2006) and more equipment was needed to care for him, Martin moved to the registered care service in November 2013 that he lived in for the rest of his life. Martin moved to the registered care service after a spell in hospital recovering from a UTI. It was during this spell in hospital that Martin lost some of his life skills and his mobility further deteriorated.

The last three years of Martin's life

Healthcare offered:

- Martin received health care from his GP, including an annual dementia review, which Martin was last invited to attend in October 2015
- Martin had regular reviews with his consultant, the last of which was on 12 September 2016 when Martin's consultant visited him at his registered care service (she had previously visited Martin at his MacIntyre service on 3 earlier occasions in 2016)
- Martin had occupational therapy assessments when his health began to decline in 2013
- Martin's mobility was assessed several times by a physiotherapist
- Martin had dietician input in 2014 due to weight loss
- Martin received support from the Speech and Language team who diagnosed his dysphagia
- Martin received care from the continence service
- Martin received support from a dermatology specialist
- Martin would see the dentist – his last appointment was in July 2015
- Martin would have appointments with the optician, audiologist and chiropodist
- During his end of life care, Martin had his medication administered by district nurses

Adaptations to Martin's support:

- Martin had a wheelchair and a tracking hoist to assist with his transfers from his bed to his wheelchair
- Martin had a reclining chair that was bespoke to his needs, before Martin became confined to his bed
- Martin spent most of his days in bed in the last year of his life. Martin had a profiling bed and a pressure relief mattress. Martin would be repositioned every 2 hours when in bed and a wedge was used to keep Martin off his back to reduce the risks of pressure ulcers
- Martin initially used pads for his incontinence, but when he became more immobile and urine began to affect his skin, Martin was fitted with a convene to keep as much moisture as possible away from his skin. In bed, Martin had disposable sheets to allow air to circulate and keep his skin as dry as possible. Barrier creams were also used.

How Martin and the staff team worked together:

When Martin moved to MacIntyre's registered care service he was already a poorly gentleman with multiple health problems. The spell in hospital that directly proceeded Martin's move to MacIntyre's registered care service hadn't been a very positive experience for Martin; he lost a lot of skills and independence that due to his Alzheimer's Disease he would never regain. Martin wasn't able to make conversation and staff had to get to know Martin and find ways to support him effectively, which they did. At every stage of Martin's life staff tried to support him to have choice and control. Staff nurtured Martin's passions, creating a memory box for him and, acknowledging what lay ahead, ensured that long-term planning for Martin's deterioration and EOL was in place well in advance of it actually being needed.

Family and peer involvement

Family: Martin's cousins visited him regularly, and one of his cousins was particularly active in his life, advocating for Martin and ensuring his views and wishes were always represented.

Peers: Martin's housemates had multiple health problems themselves. They generally coped well with Martin's declining health, supported by the staff team.

Training and support for MacIntyre staff:

The team supporting Martin attended Dementia Special Interest Group (DSIG) meetings, utilised the MacIntyre DSIG training pack and dementia e-learning, and had support from Beth Britton, MacIntyre's external dementia consultant (non-medical). Beth visited Martin's service in April 2014 and August 2015 to support staff in their care of Martin – issues discussed on these visits included nutrition, hydration and dysphagia, environment, choice and control, life story work (Martin's memory box was later created by his staff team), communication, medication (see note below regarding poly pharmacy and the successful reduction in Martin's medication), mobility and EOL. Beth returned to Martin's service in September 2016 as part of MacIntyre's Dementia Project work.

The use of medication:

Due to his numerous health conditions, Martin was prescribed a multitude of medications during his years within MacIntyre services. When Beth visited Martin's service in August 2015 she highlighted concerns about the quantity of medication Martin was taking (10 different oral medications) and the risks of poly pharmacy. Having advised staff to review Martin's medication, staff did this and in notes dated January 2016 (the time Martin began receiving palliative care), his medication had been reviewed and reduced to just Levothyroxine (thyroid med), Omeprazole (indigestion med) and Sodium Valporate (epilepsy med). Staff noted that this had been a positive experience and in all likelihood, made Martin far more comfortable as he was no longer experiencing any adverse medication side-effects.

Significant factors that enabled Martin to live well with dementia:

- Primarily Martin's character and personality enabled him to cope remarkably well with the health challenges he faced. Martin generally approached life with a smile on his face, and aside from an understandable dislike of personal care, Martin was a joy to support because he reciprocated the fun and kindness staff showed him.
- The role Martin's cousins took in his life was vital to Martin living well with his dementia. Martin's cousins did their utmost to fill the void left by the loss of his parents and siblings, bringing social interaction into Martin's life that he very much enjoyed and looked forward to. They also effectively advocated for Martin and remained consistent figures in Martin's life throughout his declining health.
- The knowledge, person-centred approaches and commitment shown by the MacIntyre team supporting Martin cannot be underestimated in contributing to Martin living well with his dementia. Despite Martin's declining health staff remained upbeat, rose to every challenge, sought additional healthcare support when it was needed, and remained utterly dedicated to giving Martin the very best quality of life possible.
- The support of external healthcare professionals was important both to Martin living well with his dementia and in enabling MacIntyre staff to provide the very best care for Martin.

Martin's end of life care

Timeline:

- Martin began receiving palliative care at the beginning of 2016
- In the weeks leading up to his death, Martin had been exclusively in bed, spending most of his time sleeping and his health had deteriorated
- Martin was admitted to hospital on 13 October 2016 because of a chesty cough and seizures, and discharged after 3 nights following antibiotics and an increase in epilepsy medication
- On 31 October 2016 Martin lost his swallowing reflex completely
- Martin's GP visited him on 1 November 2016 and EOL care was put in place. Staff noted that Martin did not appear to be in pain, agitated or distressed
- A syringe driver was fitted on 2 November 2016, and district nurses visited to administer controlled drugs as required
- Martin died on 5 November 2016 at 4am

The role of MacIntyre staff:

Staff took care to provide 24 hour care as per the shift pattern in place. Martin had regular full body washes, was repositioned every 2 hours, and kept comfortable with mouth care. Martin was never left alone, and was supported by staff who had the knowledge of what Martin enjoyed and were able to talk to him about these aspects of his life. Staff also kept meticulous records of Martin's condition and liaised with family and external healthcare staff, including palliative care support.

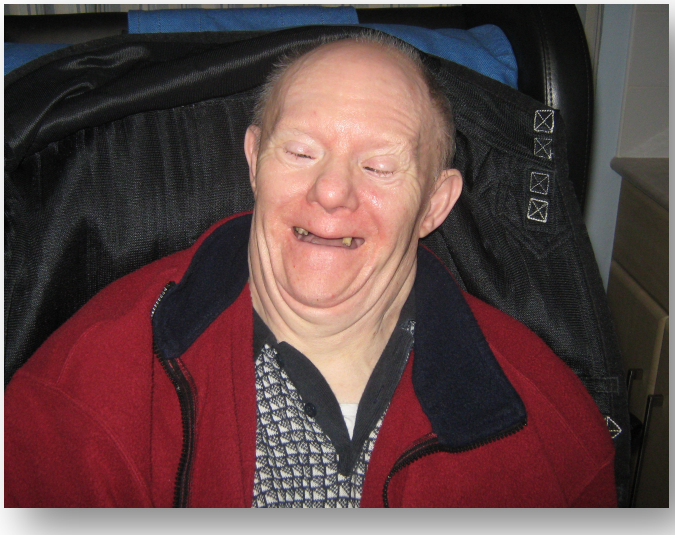
Plans for Martin's end of life:

- Staff had EOL training in preparation. The service was also visited by a palliative care nurse and meetings and plans were put in place for Martin's EOL
- Guidelines were created in the event of Martin's death regarding things such as protocols for staff and notifying Martin's family and for calling paramedics/ ambulances
- Notes from a meeting between staff and Martin's cousin in January 2016 document a discussion about Martin's deteriorating health and what should happen in the event of Martin's death. Martin's cousin wanted to be kept informed regarding Martin's health, that he was to remain at his MacIntyre service with staff he knew and his own possessions around him, and that she had a funeral plan in place and would make the arrangements with help from staff
- A document was filed following Martin losing his swallowing reflex on 31 October for all staff to sign. This document guided staff in:
    - Mouth care
    - The role of the PEPS (Bedfordshire Partnership for Excellence in Palliative Care) team (who would arrange for a district nurse to administer controlled drugs)
    - That 'under no circumstances is an ambulance to be called'
    - How staff should interact with Martin (reading to him, stroking his hand, talking to him and not leaving him alone)
    - What to do in the event of Martin dying (calling the doctor, specific undertakers to be used)
    - Being mindful of other housemates
    - Staff asking for support themselves from their peers and management if they needed it

Did Martin have a DNR?

Yes. In separate notes, it is documented that antibiotics were to be prescribed by a doctor when needed and to be administered to Martin at home.

Martin's GP's viewpoint was that antibiotics fight infection and can provide pain relief, but don't necessarily prolong life.



Who was involved in Martin's end of life care?

The whole of the staff team at Martin's registered care service, Martin's family, Martin's GP, PEPS (Bedfordshire Partnership for Excellence in Palliative Care) and district nurses.

How was Martin involved?

Martin was largely unresponsive during the last days and hours of his life, but he had the reassurance of being in a place he called home, with familiar staff caring for him and his family regularly visiting. Martin's privacy and dignity was of paramount importance at all times.

How was Martin's family involved?

Martin's family was always keen for Martin to remain at his MacIntyre service through his EOL care, which was achieved successfully. Martin's family visited him regularly in the last few days of his life, enabling them to spend quality time with him.

Significant factors that enabled Martin to have 'a good death':

- Plans were put in place early and the staff team were as prepared as they could be
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Conclusion

As much as anyone can know, it is felt that Martin's death was a peaceful, pain free experience for him, and an example of what can be achieved for a person with a learning disability and dementia, in a social care setting, with appropriate and timely support from healthcare professionals.

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MacIntyre

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