MacIntyre

Providing support...your way

Learning Disability and End of Life Care: Alison's Story

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What we will talk about today

- Brief introduction to MacIntyre and our services
- Tell you about Alison, our pioneer
- Reflect on the challenges in accessing appropriate healthcare services
- Moving forward

MacIntyre
Dementia Project

About MacIntyre

We provide learning, support and care for more than **1,500 children, young people and adults** who have a **learning disability and/or autism**, at more than **150 services** across England and Wales.

The MacIntyre way

- Encourage ambition
- Have Great Interactions
- Give and receive respect
- Be person centred
- Place the individual at the centre of their service
- Promote reflective practice and continual learning

Alison, our pioneer

- First person we supported through their end of life journey
- Alison had a diagnosis of Dementia, which sadly was not diagnosed until the later stages, as she was just 47
- We had a difficult journey in getting the initial diagnosis
- This was made more difficult due to her learning disability

Difficulties faced

- Staff and her friends' understanding of changes as Alison was not viewed as elderly or unwell at that point
- Not all changes seen
- Not initially recognising and recording changes in health
- Not knowing who to connect with other than GP

Alison’s End of Life Care

- Alison died in hospital, as we were not equipped to support her at home due to her needs; we had limited knowledge and training around what to expect at that time
- We took Alison's room to the hospital, all the things she loved and she was supported by the staff there
- There was a persistence of medical professionals wanting to keep treating, even though at this point it was evident that she was deteriorating and her quality her life had diminished greatly
- Working together with the family and professionals enabled better outcomes

Our learning moving forward

- The need for recording peoples health, the introduction of Health calendars and training
- Making connections with other Health professionals, including forging better links with local GP practice & local Hospice
- Getting people on the Gold Framework
- Working with authorities to ensure funding agreed for change in needs

Our learning, continued

- Being proactive not reactive to situations
- Training our staff, upskilling them
- EOL planning, talking to families and the people we support around what they want
- Talking about health changes and ageing including death openly
- Being able to support people to have a good death has helped with the grieving process

Our learning, continued

- We are supporting an ageing population, with ever increasing health needs
- This journey has really only just began, but we feel that we are certainly better equipped to deal with what's ahead
- We are not afraid to question or be persistent in our quest to ensure that we get the best support for the people in our care

Any questions?

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Thank you for listening

For more information please get in touch.

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