



Pen Portraits

Easy Read

NHS England and NHS Improvement



Contents

3	Introduction
4-5	Pen Portrait 1: Family, Friends and Community
6-8	Pen Portrait 2: Communication Developed Well
9-10	Pen Portrait 3: Proactive End of Life Preparation
11-13	Pen Portrait 4: Support through Care Coordination

Introduction



We wanted to share some of the experiences that people with a learning disability and their families have had in Oxfordshire.



These are some 'pen portraits' that look at the lives of 4 people whose cases were reviewed in 2020-2021.



A pen portrait tells you all about a person and their life.



It was really important to understand the people and their lives when reviewing their cases and to know what did and did not help.



Here is some information that we learned when looking into their deaths.

Pen Portrait 1: Family, Friends and Community



Fred was in his 70s when he died.



Family was really important to him and he was supported to live with this family all of his life.



Friendship was also really important to Fred.



He loved his volunteer jobs in Oxfam, a care home and working with furniture.



Going to church and being part of the community was a big part of his life.



Spending time with friends, dancing and wearing a nice suit were some of his favourite things to do.

He loved to be sociable and loved every party he was invited too.



When the Covid-19 restrictions came in, Fred couldn't go out and see his friends and family.



This is when his family really noticed that he wasn't himself.

His health and wellbeing started to go down.



Fred's review showed just how important relationships with friends and family can be for your quality of life.



Having connections in the community is really good for confidence and self-esteem.

Having a community based role is also very important.

Pen Portrait 2: Communication Developed Well



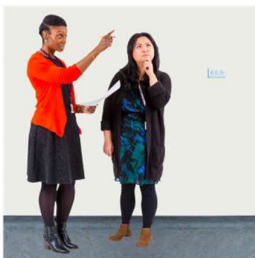
Agnes was in her 70s when she died.



She was friendly and was able to use her voice to say what she wanted.



However, sometimes people thought she understood more than she really did.



Her support workers would have to double check that she understood what they were saying.



They also found that she would change the subject if she didn't want to talk about it.



If Agnes was not getting the attention she wanted, she could get upset and her behaviour could be challenging.



Agnes liked to be involved in planning meetings at her home.



She also really enjoyed going to her day service which she would call her 'Work'.



Agnes had a special relationship which she was supported to keep until she died.



Agnes' review shows that knowing someone really well is key to them getting the best care and support.



It is important that all services work together with people who know the person well and that they are involved in their care.



An important part of this is communication.

Sometimes communication is not just about understanding the things others say but also understanding their behaviour.



It's important that all services support people to make their own choices by supporting them to understand the consequences of their choices and make a choice that is good for them.

Pen Portrait 3: Proactive End of Life Preparation



Stanley moved away from his family when he was 8 years old but he had a good relationship with them all his life.



In 1990, Stanley moved into a supported living service where he lived until he passed away.



He was friendly but liked his own space to do jigsaw puzzles and play cards.



Stanley worked with his GP and support team to get used to going to the doctors and having treatments.

They were also able to have conversations with him about his end-of-life care. Stanley was able to make his own plan for his funeral to make sure it was just what he wanted.



Positive discussions and being open about end-of-life care and plans meant that Stanley was able to spend the last week of his life at home where he was happy.



Thinking, talking and planning for one's death is normal and healthy.

Death and dying should not be an banned topic.

Pen Portrait 4: Support through Care Coordination



Margaret was in her late 60s when she died.



She was really friendly and got on well with most people.



Margaret lived independently in a retirement home.



She had support from Personal Assistants (PA) who helped her go out and about to do her shopping and to do some personal care.



Her PA's also helped her to book and get to her medical appointments.



Margaret did not need support in the appointments, but she told her supporters what they needed to know.



She had a long-term health condition which meant she was often in the hospital.



Sadly, Margaret had not had her annual health check since 2013 and missed other health reviews.



This meant Margaret's health care plan was not up to date and those who were supporting her may not have known important information about her medical needs.



Margaret got very sick very quickly and unfortunately, neither her nor her family were able to be involved in her end-of-life care decisions.



If Margaret had spoken with her carers more about her health, they could have helped her to make choices about the care she wanted at the end of her life.



Margaret's story shows us how important it is to have annual health appointments to check how we are.



While privacy is important, it is also really important that those who support us know us well and know about our health conditions so they can help us to plan for the future.



This Easy Read report was created by My Life
My Choice.