

## LeDer Case Study: Roger's Story

Roger was 68 years of age when he sadly died, his learning disability recorded was Downs Syndrome he appeared to have led a happy and healthy life, and during his last 6 months of life he did not present with any serious illness. The coroner's report concluded his death was due to a sudden cardiac arrest, Ischaemic Heart Disease, Left Ventricular Hypertrophy

### Life History

The reviewer identified someone (Kay) who was close to Roger. Roger lived at Children's Home since the age of two and a half years old when his father forced a separation from his mother

Kay spoke how her parents worked at the Childrens Home, her mother was head of care, Throughout the years most of the family worked at the Home. Roger had a family-based upbringing, which was in a caring and loving environment. Roger made lots of close relationships and was extremely popular.

She continued that to say that Roger was a very kind, helpful happy and caring person, who liked to help other people and people enjoyed his company. He was very actively involved with school life, he enjoyed working in the school grounds, growing vegetables, sweeping leaves, planting flowers and other activities of ground maintenance.

Roger was very creative, he loved to colour, he also enjoyed watching animated films. He would insist that night staff wrote up his diary each night before bed and would not go to bed before this was done. He loved his routine and there were times when he could be stubborn and want things his own way, with inventive support to help him, Roger would eventually do what was required

When Roger was 16 years old his birth mother made contact and they developed a good friendship, but he would always refer to her as Mrs Smith. When his mother became ill, she entrusted his welfare to the head of care at Childrens Home.

When Roger's Mother passed away Kay became his legal representative. She talked about how Roger was a much-loved member of the family and he loved being part of the family and joined in lots of family fun. Roger was very caring towards the children over the years, and they adored him.

When Roger was 19 and could no longer live at the Childrens Home he went back to the north of England and was found a home in supported living accommodation, this was not an appropriate move and he moved back to the Midlands. Roger was invited to live with Deputy Head of Care (Mary), who had become a friend, and lived in a cottage within the grounds of the home.

He was very happy living in the cottage and became a part of the estates ground maintenance staff team. He was hard working always willing to help others, happy and fun to be around. Roger was well known for his heavy-handed approach and

things just breaking, all who knew and loved him accepted this trait and he has left some happy and funny memories.

When Mary retired, Roger was asked if he would like to continue to live with Mary and they moved to a new home closer to Kay. Roger would joke that they had lived together for so long she was a bit like a wife. During his later years he continued to keep active by walking, going to the pub, garden centres, car boot sales, visiting friends and attended two clubs on a weekly basis.

Roger loved being with people, and was always excited when out dancing, going to the theatre and he was a lot of fun to be with. He enjoyed his holidays abroad with Kay and her family, although he said he did not like heights.

### **Roger's family thoughts about the support from Services:**

Kay was satisfied with Roger's access to health care and the support he received from Primary Care Health services. Over the years Roger was supported to attend GP appointments when required, he attended Learning Disabilities Annual Health Checks, which included blood pressure had regular blood tests for Thyroxine levels, regular medication reviews, ear drops/syringing he and was given health accessible information had received all vaccinations including both Covid 19 vaccinations.

Roger refused support for any weight management, although he was not significantly overweight, he was supported by Mary and Kay to maintain healthy balanced diet. He was at his home when he suffered a sudden cardiac arrest

Roger had never been referred to any Learning Disability community services, and Kay was not aware of services at Ridge Hill. Roger had always coped with mainstream health appointments and Kay had no concerns with any changes in behaviours or memory.

In 2019/20 Mary (who Roger lived with) began to show early signs of Alzheimer's and Kay was a little concerned regarding possible future needs for both Roger and Mary.

A referral was made to Local Authority, and Kay received a telephone consultation in April 2020 when the requirement for a stair rail and bathroom assessment was agreed to support Roger with any future needs and assessment for Mary. There were no further phone calls for either until Kay called back in July 2020, after Roger's death, Kay was extremely upset with the lack of support from Local Authority.

While this had no direct link to Roger's death, she was still visibly upset by the lack of care or concern from Local Authority.

### **The views of the GP:**

The GP talked about Roger having a quite good level of understanding and with the support from carer, he did have capacity to make some decisions regarding his health. Roger had not been seen by a doctor within the last 6 months prior to his

death which is why his death had been reported to the coroner. There were no requests for, or cancelled GP appointments.

There were no records of previous heart attacks or angina, and Roger was not approaching End of Life. In 2020 A QRisk2 cardiovascular disease 10-year Risk assessment scored 19.7%.

Roger had not been asked about completing an Advanced Care Plan, this is something he will address with practice staff as this is something that should have been considered

Roger had been asked to book an appointment to discuss medication. Roger did not attend the appointment to discuss prescription for Statins, but his GP felt this was not a significant risk in relation to Roger's death. Roger's GP highlighted that after this review that the surgery will look at a system to follow up and contact people when it is suggested they make further appointments.

The annual health check template indicates there were discussions regarding behaviour and memory and no concerns were reported. There was no evidence that he had been offered any type of dementia screening which should have been offered.

### **Learning and Good Practice**

1. The learning disability annual health check were completed yearly but due to Covid restrictions his last health check was completed over the telephone with his carer. Recommendation annual health check should be completed face to face to ensure that cardiac assessment can completed as per the Royal College of General Practitioners – Syndrome Specific defects.
2. Roger could have accessed proactive dementia screening from the age 30 but there no evidence if this had happened – Recommendation to promote the Dementia Screening pathway across Dudley
3. There is evidence that paramedics followed procedure in regard to CPR and made every attempt and effort to resuscitate
4. Lack of follow up from LA following an assessment for aids and adaptations - Recommendation LA rep at panel to share the Rogers case study with Adult Social Care