The benefits of good end of life care for patients with autism

Jean Charalambous, Community Nurse

Valerie moved into supported living in 1999, when her mother was no longer able to support her to the same level she had before. Valerie made friends quickly and settled well. Valerie developed relationships with the house staff, providing them all with nicknames. Valerie enjoyed going to her local pub for a beer, listening to music, going on holidays abroad, dancing and singing.

Valerie’s health began to fail in the early part of July 2013, requiring her to undergo surgery. Staff supported her during her hospital stay and post-discharge within a rehab setting. Valerie bounced back, regaining her lust for life on this occasion. During August 2014, worrying symptoms presented, indicating that her health was once again in trouble, and Valerie somehow lost her sparkle. Valerie communicated less, and spent long periods of time sleeping. The house team contacted the GP, who swiftly arranged for Valerie to be admitted to her local hospital to receive treatment. Valerie was quickly diagnosed with endometrial cancer, with a prognosis of weeks rather than months, plus Valerie was unlikely to be a candidate for surgery given the extent of the cancer.

The supported living home requested for Valerie to be cared for at home even though they had little experience of end of life care, and knowing this would challenge them in a number of ways emotionally and procedurally. Whilst realising that home was the best place for Valerie given her relationships and familiarity with the environment, the staff were aware that this would also challenge the other ladies living in the home. The house staff needed to work with a number of health professionals: Learning Disability Team, OTs, Physiotherapists, Palliative Care Team, GP and District Nurses. This would enable the right care, right equipment and right support for Valerie to remain as comfortable as possible within an environment she was familiar with.

Valerie had lived happily in the house for sixteen years, and it was clear that the relationships she had built with staff and other housemates were a vital part of ensuring her mental wellbeing was maintained. Staff also had to ensure their own well-being as the care for Valerie challenged them personally, and some requested counselling in order to help them talk to each other, to family members and to the other ladies in the home who would be asking questions about Valerie. The staff developed a strong network made up of external agencies, and through this support, the bond between staff members grew.

Valerie passed away peacefully at home in March 2015, surrounded by her family and care workers.

The house team have had time to reflect on this experience, and given the level of support provided from outside agencies, would now consider providing similar care to other customers as we have gained so much strength from Valerie’s situation. The house team state that they “learnt that nothing is impossible, and that with strong working teams, anyone can be supported through the end of life experience, even in a Supported Living environment. Going forward, we are working on some training around end of life experiences as it should not take something like Valerie’s experience to openly discuss such issues”.

If you are interested in reading more about best practice for end of life care, The Palliative and End of Life toolkit gives a useful guide. The GMC have launched a series of end of life resources to assist GPs in supporting their patients. Breaking bad news has also provided a series of resources to ease the process of breaking bad news to people with intellectual disabilities and/or autism.