

Death and Dying Seminar Series: 19th September 2017

Improving Access to Palliative Care for People with Learning Disabilities

Speaker: Louise Jenkins, Strategic Liaison Nurse for Secondary and Tertiary Care

Reviewer: Kerry Jones, Lecturer, Open University

Louise introduced the seminar on end of life and learning disabilities by providing an overview of some of the health conditions that are prevalent for people with learning disabilities and which for many are experienced since childhood. As a consequence people with learning disabilities have an average life expectancy of 63 years for women and 65 for men compared to the general population where people can expect to live on average, for 83 years. For some individuals experiencing intellectual disabilities, life expectancy is considerably lower again with 22 percent dying before the age of 50 years of age. The reason for this sobering statistic is attributable to delays in assessing and investigating illnesses as well as delays in treatment. Moreover, a lack of recognising when someone with a learning disability is nearing the end of their life is compounded further by difficulties in receiving adequate care and attention including sufficient opioid analgesia towards the end of their lives.

The seminar was well attended by a diverse range of health and social care professionals who shared their experiences of care of people with learning disabilities and their ability to provide optimum care. A significant part of the discussion centred upon having discussions about end of life care and the tools available to facilitate such discussion. While Louise was able to highlight good models of practice with her colleagues and felt supported to do so, supporting people with learning disabilities towards the end of their life remains variable. While it is recognised that there are specific champions who advocate on behalf of people with learning disabilities the reality is they often do so in isolation which in the seminar revealed the policy to practice gap and the real need to have sound, coherent and effective plans which support professionals and care givers. It was apparent that there is a real will and effort to provide the best available care and Louise was able to provide a great deal of insight and practical applications through the 'Top to Toe' guide available on the Death and Dying seminar site at The Open University.

Louise continues to develop and deliver education to health and social care professionals and to highlight the needs of learning disabilities towards the end of their lives. While we continue to strive forward, there is some way to go. Yet, there is much to be gained by initiating and implementing the findings of the LeDeR Mortality review process that Louise discussed and to draw strength from the outcomes that lead towards a better journey for people with learning disabilities as they reach the end of their lives.