

End of Life Care – *Learning Disabilities*

Developing person centred skills to support adults with learning disabilities at end of life and at times when they experience, death, loss and grief that is past and current.

What is this programme about?

This programme is about exploring good practice and the needs of learning disabilities Service Users and families you support. It challenges staff to explore their own perspectives and experiences of palliative care and grief, as well as to reflect on meaningful and effective ways to develop and maintain resilience and wellbeing for Service Users, families and themselves. There will be a strong focus on issues in learning disabilities.

Who is the programme for?

This programme is for any staff working with adults with learning disabilities.

Why this programme was developed?

Death and dying matters are often viewed as a taboo and difficult subject in communities and ironically in health and social care too. This programme is about raising awareness of the fact that people with learning disabilities are some of the most marginalised groups in society. Many of the 1.5 million people with learning difficulties in the UK have to cope with experiences of dying, death and bereavement without being fully informed about what is going on. They also face many barriers to good end of life health and social care when they need it.

People with learning disabilities need

- support to develop their awareness about death and dying
- person centred end of life care needs to involve family, friends and all paid carers
- tools to enable communication about their illness and end of life journey
- reasonable adjustments need to be made to enable advance care planning
- their needs, wishes and preferences to be heard

Aims:

- To provide the underpinning knowledge required to deliver appropriate care and support to Service Users and their families during the end of life stages of their illness.
- To encourage learning disabilities teams to develop courage and competence around end of life care issues.

Course content

- Explain what is meant by the term 'end of life care'.
- Discuss their role in supporting people in end of life stages
- Explain Advance Care planning and Advance directives
- Symptom management
- Unexpected death
- Identify other professionals they can involve in end of life care
- Discuss what makes a good/bad death experience
- Discuss the specific needs of people with learning disabilities
- Give an overview of 'last offices'
- Discuss attitudes and fears towards death and dying
- Consider impact of loss and grief on staff



JoCo Learning & Development
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