Introduction
People with a learning disability may experience more losses during their lifetime than the general population\(^1\) with an increased risk of experiencing disenfranchised grief\(^2,3\). Some live with a life limiting illness from birth and all are at risk of developing one throughout their life time\(^1\). As palliative care aims to care for all living with a life threatening illness and those who grieve their death\(^4,5\) there is a responsibility to ensure equity in care for those with a learning disability and their families\(^6\). Collaborative working between palliative care and learning disability professionals is essential to ensure that the individual needs of the person remain paramount\(^3\).

Education
Recognising that professional carers need opportunities to develop knowledge and skills to support people with a learning disability through losses in life, a collaborative partnership was formed to develop and deliver an education programme.

Aim: To enable professional carers working with people with a learning disability to explore loss and bereavement during life and following a death.

The programme
The programme is structured over two days with a two week gap between days to allow participants time to reflect on practice. Content includes theories of loss and bereavement; types of losses in life and death (see Figure 1); how people with learning disabilities express their grief and practical and creative approaches to offering support. Follow up is available to participants from the learning disabilities team and individualised education sessions offered at the time of need.

Evaluation
The course is evaluated on the day and at six months with very positive comments:

“Both days were helpful as I learnt new ways of how to talk about loss and how to approach the subject with service users”

Changes in Practice
Significant changes to practice have been noted and an example seen in one unit where changes have included developing a charter to support their clients, families and staff through loss, creating a garden of remembrance and using a memory tree (see Figure 2).

Conclusion
People living with a learning disability have the same right of access to support in order to cope with loss and bereavement as the general population. This collaborative education programme has offered professional carers an opportunity to develop the knowledge and skills required to support individuals and change practice.

References

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